

## ABSTRACT

PROHN, SEB MACKENZIE. A Grounded Theory of Social Inclusion for Postsecondary Education Students with Intellectual Disability. (Under the direction of Dr. Craig C. Brookins.)

Students with intellectual disability (ID) now have opportunities to attend college. In 2014, students with ID accessed college through 221 Postsecondary education (PSE) programs in the United States (Think College, 2014). Students join PSE programs to acquire personal, social, and vocational skills to increase the likelihood of an independent and employed future. This study gave six students with ID, who were accessing college through a PSE program in the 2012-2013 academic year, the opportunity to assess their social experiences in the college community. Students' typically developing peers, known as "natural supports", who assisted Students in meeting the demands of the college environment, also assessed Students' social experiences in college. Data were collected through student interviews as well as natural support focus groups and surveys. Quantitative results described Students as socially supported by friends and rarely lonely. Qualitative data were coded and analyzed using a constructivist grounded theory process to develop a social inclusion theory. The resulting theory described social inclusion as a function of belonging and attributed worth in context. Greatest opportunities for sustainable social inclusion were described as occurring in contexts where Students had maximal control over their social choices and experiences. Recommendations are provided to assist the PSE program and others like it in developing strategies to increase student self-determination and opportunities for social control.

A Grounded Theory of Social Inclusion for Postsecondary Education Students with  
Intellectual Disability

by  
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## **DEDICATION**

This study is dedicated to all the Students and Supports who, in sharing their experiences, have created a path towards more inclusive social experiences for all members of all campus communities.

## **BIOGRAPHY**

Seb Prohn is a Western North Carolina native. Along with his sister, Kallie, Seb was raised by parents who, as special educators, taught students with a wide range of (dis)abilities. Seb was a Teach For America corps member in South Louisiana-- an experience which shaped his interests in social justice and community psychology. Currently, Seb lives in Asheville with his wife, Joanna, and he works with college students with intellectual disability. North Carolina State University has always been a second home for Seb. He holds a B.A. in sociology and a M.S. in psychology from NCSU.

## ACKNOWLEDGEMENTS

As participant-researchers, the Students in this study deserve considerable credit. They actively collected data to describe their social experiences. Each student wanted a future with increased opportunity for others with disabilities, and through their research they have made an indelible impact on several futures, including my own.

Dr. David Westling and Dr. Kelly Kelley gave more than their blessings for this research-- they shared their knowledge and experiences. Their insight challenged me to examine the intersections between special education and community psychology.

I would like to thank my parents who gave me endless love through the crests and troughs of graduate school. When I was young, they made sure I was exposed to the strengths of a diverse community. Ken and Dianne Prohn have spent their lives making the community a better place. They have set a high standard. I could not be more proud of my parents.

Finally, I'd like to thank my wife, Joanna, for her unwavering support. She became too familiar with this dissertation that was present on holidays, vacations, weekends, and early mornings. Joanna could have easily despised my work. Instead, she just understood. She even edited the entire draft before it was submitted to my committee! I love her with all my heart and I look forward to our future...and our first child who is on the way!

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*I always danced on my own. I never really danced on a college campus, and I really did want to try ballroom dancing, and I finally did it...it was hard actually, but it's just like "I got through it."*

Kerri, second-year college student

## **CHAPTER 1: INTRODUCTION**

### *From Institutions to Universities: A General Background of Study*

One of community psychology's founding fathers, the man who coined the term "psychological sense of community," Seymour Sarason, wrote the forward to Blatt's *Christmas in Purgatory: A photographic essay on mental retardation* (1966). Blatt's book, to build awareness and catalyze change, documented humans with disabilities who were warehoused in substandard institutions.

Sarason stated "if one thinks that defective children are almost beyond help, one acts toward them in ways which then confirm one's assumptions." (in Blatt & Kaplan, 1966, pg. ii). He evoked community psychology through what became a founding principal of the Society for Community, Research and Action and reminded readers that "Human competencies and problems are best understood by viewing people within their social, cultural, economic, geographic, and historical contexts" (<http://www.scra27.org/about>). Isolated asylums removed individuals from the 'outside world' and its social spheres. People with intellectual disabilities (ID) were not extended opportunities to build capacity, to participate, or to contribute to society.

Dreadful conditions within institutions, such as those captured in Blatt's 'photographic essay' caught public attention resulting in efforts for change. Notably, in 1979

the Center on Human Policy at Syracuse issued *The Community Imperative*. This document expressed the values and opinions of people from the field of intellectual disability policy and research, including parents and people with disability. It stated that all individuals with ID should have access and be embedded within communities rather than held in institutions. Objectives within the domain of Educational Programming and Human Services directly challenged the ideals underpinning long-term institutionalization, including:

- All people, as human beings, are inherently valuable.
- All people can grow and develop.
- All people are entitled to conditions which foster their development.
- Such conditions are optimally provided in community settings. (Center for Human Policy, 1979)

Changing a culture that viewed individuals with ID as developmentally static was a critical step for the promotion of inclusion in communities and educational settings.

In the three decades following the release of *The Community Imperative*, long-term institutional residencies became rarer. Despite opportunities to exist within communities, people with ID still experienced large degrees of marginalization. Compared with other students that experienced disability in the K-12 environment, students with ID were more likely to be taught in segregated settings, and they were more likely to not complete high school (Palloway, Lubin, Smith, and Patton, 2010). Also, compared to the general population, people with ID are commonly poorer (Fujiura, 2003), less employed (Yamaki & Fujiura, 2002), and less healthy (Stancliffe & Lakin, 2007). Multiple problems require multiple solutions. One path towards greater equality is through educational opportunity.

In its current database, Think College (2014), a national research and training initiative of the University of Massachusetts's Institute for Community Inclusion, included

218 post-secondary education (PSE) programs for students with intellectual disabilities. Once fantasy, higher education was becoming an option for more students, mediated by PSE programs. Most PSE programs viewed college as an opportunity for developing skills beyond the scope of academic curricula. Of the 149 PSE programs surveyed by Grigal, Hart, and Weir (2012), 34% indicated that the primary focus of the PSE program was independent living skills, and 32% said it was employment, indicating a strong focus on skills most associated with typical adult experiences. Efforts at human development to further foster independence and employability for students with ID stand diametrically opposed to institutions that functioned under the assumption that people with ID were uneducable and unemployable. Historical shifts in thought helped make college more accessible, and built a foundation for a dramatic increase in PSE programs over the last 20 years, a trend which is expected to continue (Grigal, Hart, & Weir, 2014).

Growing openness in tertiary education became possible through more than changing opinions. Legislation was passed that further mandated opportunity for people with ID in educational settings. The Individuals with Disabilities Education Act (IDEA, 2004) governs the ways education services are provided for people with disabilities from birth to approximately 21 years of age. The reauthorization of IDEA in 2004 explicitly defined Free and Appropriate Public Education as educational services that meet the unique learning needs of students with disabilities and prepare students for further education, employment and independent living (U.S. Department of education, <http://www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html>). IDEA also requires

that students are placed in educational environments that are integrated to the maximum extent possible. When appropriate in kindergarten-12<sup>th</sup> grade, students with disabilities must be included with their typically developing peers.

Before the introduction of IDEA, the Higher Education Opportunity Act (HEOA) of 1965 sought to make college education accessible to more racially and economically diverse student bodies. The 2008 reauthorization of HEOA provisioned college access for students that were eligible for free and appropriate public education under IDEA. The reauthorization also oversaw the development and expansion of high quality, inclusive postsecondary education (PSE) programs for students with ID.

Federal funding advanced the construction and maintenance of pilot Transition and Postsecondary Programs for Students with Intellectual Disability (TPSIDs). The new programs served as model demonstration sites to build best practices for inclusive and accessible college education for students with intellectual disabilities. As a result, physical spaces such as college classrooms, libraries, dining halls and recreational areas, were increasingly inclusive for people with ID (Weir, Grigal, Hart, & Boyle, 2013- profiles and promising practices). Because it was novel, little was known about facilitating college experiences for students with ID or the impact college would have and even less was known about the daily experiences of this newly included population of students.

### **Statement of the Problem**

Given that PSE opportunities for students with ID are still relatively uncommon, most discussions on the topic either describe existing PSE programs or propose strategies for implementing these programs at institutions of higher education. To date, proving the



feasibility of PSE programs has been prioritized while student and program specific outcomes lag further behind. For example, Grigal & Hart (2009) described existing PSE typologies as either substantially separate, hybrid or inclusive individual support models, while Blumberg, Carroll & Petroff (2008) outline a liberal arts approach to PSE programming. Studies on PSE outcomes have been less frequent, but have documented the effects students with ID have on their campus communities by measuring typically developing peers' attitudes about diversity and people with ID (May, 2012; Westling, Kelley, Cain & Prohn, 2013). Students who participated in PSE programs also had better employment outcomes such as more employment and higher wages than their peers with ID who did not extend their education beyond high school (Zafft, Hart & Zimbrich, 2004; Migliore, Butterworth, and Hart, 2009). No studies have described or explained the effects of social inclusion on college students with ID living in a college community. With little understanding of inclusive college experiences and PSE program outcomes, Grigal et al. (2014) stated, "the most critical questions have yet to be asked or answered. What effect does a college education, in its many iterations, have on...people with intellectual disability?" (p. 289).

To recruit students, PSE programs describe the quality of their university's social climates. Specifically, campus environments are often advertised as socially supportive and inclusive—two environmental elements that have been linked to self-confidence and quality of life (Hall, 2005; Miller & Chan, 2008). But, describing PSE programs as "inclusive" leaves much to the imagination. Does "inclusive" mean students take college classes with typically developing peers? Does it mean students live on campus in integrated student

housing? Does it mean all campus facilities are made available? Does it mean that students participate in reciprocal relationships? Most programs describe spatial inclusion. Students access classrooms, dining facilities, sporting events and other physical spaces on campus. Yet, social isolation is not remedied by geographical inclusion alone.

To date, investigations of social inclusion for students with intellectual disabilities in college settings have not been attempted. Social inclusion has however, been examined for people with disabilities in a variety of disparate contexts including recreational sports leagues (Grandisson, Tetreault, Freeman, 2012), neighborhoods (van Alphen, Dijker, van den Borne & Curfs, 2010; Dijker, van Alphen, Bos, van den Borne & Curfs, 2011), and a range of places and spaces within communities (Abbott & McConkey, 2006; Hall, 2009). Some social inclusion studies sought perspectives of social participants who were connected through their roles with people with ID, such as neighbors (van Alphen, Dijker, van den Borne & Curfs, 2010) or parents and care takers (Johnson, Douglas, Bigby & Lacono, 2012). None, however, sought social inclusion perspectives from college students with ID or the people closest with them in the campus community. The ways college students with ID experience campus social lives is often marketed by PSE programs as inclusive but students have been excluded from contributing to the claims. Only one study to date provided inclusive opportunities for students with ID to co-construct knowledge about their university experiences (Paiewonsky, 2011). For programs to substantiate claims of pervasive inclusion on college campuses, should not students with disabilities also be included in the research/evaluation process? PSE programs honor students' decisions to pursue postsecondary education and students have opportunities to express opinions in classrooms, values in social contexts, and preferences in

internships. To remain consistent, PSE programs need to facilitate opportunities for students to describe first-hand experiences of their college lives.

Values and methodological barriers have been antecedents to the exclusion of people with ID from research and evaluation. The former barrier doubts students' abilities while the latter doubts methods' abilities to capture first-person student experiences. Efforts to implement qualitative methods are stymied by vast differences in communication abilities, and surveys adapted for low literacy participants can negatively affect validity. Interviews and focus groups are challenged by the populations' tendencies toward suggestibility and a desire to please (Snell & Luckasson, 2009). Photovoice methods, however, have shown potential for accommodating dialogue among traditionally marginalized populations (Wang & Burris, 1997).

While imperfect, photovoice methods have proved engaging for people with ID who have limited social and communication abilities (Jurkowski & Paul-Ward, 2007). Photographs can capture experiences that might be difficult to capture in word (Larson, 2008). When researching life experiences of mothers with ID, Booth and Booth (2006) found that photographs concretized abstractions that might otherwise be difficult for participant-researchers to convey. One abstraction that photographic techniques can communicate is social inclusion and exclusion. Photographers always decide which subjects remain or which should be removed from frames. Similarly, photographs can capture separation, loneliness or membership and community, but only for individuals provided with cameras and opportunities to share their perspectives. By accommodating variations in communication and promoting skill development, photovoice dually functions as a method and

empowerment intervention, making it a promising fit for helping college students with ID share descriptions of social experiences (Duffy, 2011; Goodhard, Hsu, Baek, Coleman, Maresca, Miller, 2006).

### **Significance of the Study**

Increased familiarity with Students' lived experiences in a campus community fills gaps in knowledge. The desire for learning more about students was pragmatic. Increasing knowledge about Students' social experiences exposed some problems and further defined others, both necessary precursors to creating solutions. The value of the study exists in the processes and outcomes, insofar as they contribute to the quality of life and well-being of Students and their successors. Accessible research methods created opportunities to assess whether social experiences were fulfilling. Research processes and the meaning they allowed students to create, contributed to a social inclusion theory which targets quality of life.

### *Social Inclusion & Student Quality of Life*

The search for the presence or absence of social inclusion unintentionally captured interconnections between quality of life indicators. Quality of life for individuals with intellectual disability is often described as having eight core indicators: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, rights, and social inclusion (Schalock, 1997). From the outset, social inclusion alone was targeted, but it was discovered that social inclusion was not mutually exclusive of indicators such as personal development, self-determination, and rights. Poorly defined problems create insufficient solutions, and by further exposing the indicator interrelationships the study shows how interventions that seek to enhance any one element of

quality of life will fail without considering connected elements. Therefore, social inclusion is not possible in the absence of rights, self-determination, emotional well-being, and continuous personal development.

In addition to showing social inclusion's interconnection with other quality of life domains, this study further describes and defines the social inclusion domain. The domain has been defined through observed criteria and descriptors. If one lives in integrated environments, participates in the life of the community, and interacts with other members of the community, they are said to be socially included (Schalock, 2004). Programs are also advised to increase social inclusion by assuring people with ID have natural supports, integrated living environments, and participation (Schalock, Brown, Brown, Cummins, Felce,...Parmenter, 2002). Simplified prescriptions for social inclusion were disputed by Students and Supports who participated in this study. Their lived experiences showed observed criteria as accurate but insufficiently able to separate being in social environments and being a member of social environments. The difference may seem minute but the implications are significant for Students' present and future quality of life, and may even suggest current quality of life subscale measures for social inclusion lack content validity. When Students have an active role in research and evaluation, they have opportunities to directly and indirectly affect their quality of life.

### *Participation in Research*

The federal government has overtly stated a need for people with ID in planning programs and services to maximize benefit (Developmental Disabilities Assistance and Bills

of Rights Act, 2000), but such opportunities have been seldom reported. So seldom is participation of people with ID in evaluation that from 2000-2009, in ten evaluation journals, only one article described participation in program evaluation research by adults with ID (Jacobson, Azzam, & Baez, 2012). Including perspectives and insights of individuals with ID promotes social justice (Mertens, 1999) and can increase accuracy of study results (Chouinard & Cousins, 2009). Participation in research also creates opportunities for students to build technical and communicative capacities and validates their positions as decision-makers in their own affairs. Better communication, self-determination, and influence over services, contribute to quality of life.

Students and Supports in this study exposed barriers to inclusion and doing so offered direction for programmatic reconfigurations. The PSE program was challenged to reconsider its conceptualizations of social inclusion and their role in facilitating it. Pervasive use of natural supports in facilitating Students' social experiences was also shown to be worth reconsideration. The research also offers lessons for Supports about how to engage Students in social settings, how to better serve as facilitators for social inclusion, and how to increase their sensitivity to contexts where their assistance, for all its benefits, becomes an alienating force.

#### *Outcome Data & Consumer Reports*

Students are capable of evaluating their college experiences and their PSE programs. Criteria for excellence should be determined by how well programs meet student needs and prepare them for adulthood. Inclusion is also an appealing criterion by which students and their families choose PSE programs. People with ID seeking postsecondary education

opportunities, like their peers, are now starting to compare and apply to various colleges. Programs have disparate models, but none present evidence that their particular model is associated with Students' membership, participation, social validation, or social inclusion.

By paying tuition, fees, and other costs traditionally associated with college enrollment, Students expect access and treatment equal to that received by their non-disabled peers. Inclusion is also used for marketing. PSE programs use terms such as "fully inclusive" to draw attention from prospective students. Terms describing degrees of inclusion have neither conceptual nor operational definitions and their use is inconsistent across programs (Research and Training Center on Community Living, 2011). This study provided an opportunity for Students to describe their social experiences and insert meaning into inclusion's definitional vacuum. Definitions of inclusion, belonging, and friendship created by people with disabilities for disabilities provide a blueprint for PSE program development and a criteria for consumer reports about program quality. Presently, students actively enrolled in PSE programs have limited opportunities to communicate their social inclusion experiences to future applicants, community members, and the coordinators of their respective programs. When student stories are not shared, prospective students' abilities to make well informed decisions becomes compromised, as does the ability to provide valuable feedback that informs PSE structures and trust the accuracy of PSE claims of 'full inclusion.'

### **Key Terms**

Through the course of this dissertation, three terms are used frequently and are associated with roles, relationships, and settings through which emerged a theory of Students' social inclusion.

**Intellectual disability (ID):** Intellectual disability, formally known as ‘mental retardation’, is partly defined by an IQ range between two and five standard deviations below the norm. Two base-level requirements for ID are limitations in cognitive (or intellectual) functioning and limitations in adaptive behavior. The former describes difficulties with reasoning, learning and abstract thought. The latter is defined primarily by challenges in performing everyday tasks and routines, including but not limited to navigating ones environment, exhibiting context-specific ‘appropriate’ behaviors and up-keeping personal hygiene. Each of these factors must be diagnosed prior to an individual’s 18th birthday (American Association of Intellectual and Developmental Disabilities, 2010).

Intellectual disability is also described as a condition of human functioning (American Association of Intellectual and Developmental Disabilities, 2010). Human functioning considers, among other variables, life activities, body functions, personal activity and participation and limitations as factors that increase/decrease one’s disability. A human functioning framework for disability refers to a state and not a permanent defective condition inherent within individuals. Environmental and contextual elements are primary indicators of ability/disability (American Association of Intellectual and Developmental Disabilities, 2010). Therefore, prevailing understanding of ID is ecological. Fit between individual capacity and environmental contexts, instead of focusing on limitations alone, permit directed efforts to increase ecological support. All Students had been diagnosed by a medical professional as having intellectual disability.

**PSE Program:** Postsecondary Education Programs are accessible learning options available for students with intellectual disabilities following participation in high school education



(Grigal & Hart, 2010). In this study, PSE program primarily refers to an education opportunity that includes course enrollment and residential living at a four-year college.

**Natural Supports (i.e. Supports):** Natural Supports are paid and unpaid college students, approximately the same age as students with intellectual disabilities, that intervene as necessary to facilitate inclusive participation in residential life, course work and social & recreational activities. Supports are considered ‘natural’ when their presence within an environment is not determined by providing assistance. Students enrolled in college are natural within the college environment whereas paraprofessionals, caretakers, or family members would not typically participate in the college environment outside of support roles.

Through its subject matter, methods and resulting theory, the following study was overtly committed to greater inclusion for adults with intellectual disability. Students were valued as participant-researchers. By engaging in an inductive research process students took more ownership in creating their experiences and identities. Their descriptions built a theory of inclusion that at once is specific to the participant-researchers and universally identifiable. The present study was conducted to shape PSE program strategies and practices to enact and promote social inclusion on college campuses and in the community. The following chapter will describe the literature and methods upon which this endeavor was founded.

## CHAPTER 2: REVIEW OF LITERATURE

The study of intellectual disability spans academic fields. Some in the academy aspire to define clearer causes for intellectual disability, making medical research common. Others acknowledge the diagnoses but strive to identify and create paths to social, emotional and physical wellness. Factors contributing to wellness exist inside and outside the individual and the vast interdependencies between the two. Therefore, the literature below is both exclusive and varied. It targets research pertaining to the target population: people with intellectual disability. But, as all society's members have a stake in the wellness of marginalized populations, so do researchers. The literature review below is comprised of knowledge produced from educators, psychologists, geographers, social workers and others from various fields dedicated to wellness and validation of people with ID. The first section describes the strengths and limitations of the ways in which people with ID have been included in the research process as sharers or creators of knowledge. The second part defines social inclusion for people with ID and reviews the main themes in literature on the topic.

### *Seeking Perspective and Sharing Knowledge*

A primary aim of the present study is to include the voices of college students with ID. Doing so validates their position and the knowledge that they access daily; it acknowledges that others without disabilities cannot similarly capture or communicate these nuanced experiences. Yet, throughout their lifespans, it is not uncommon for people with ID to have others speak on their behalf, sometimes representing their interests and sometimes not. Many methods have been designed for care-workers or families to serve as surrogate voices for people with ID (Hall, 2004). Even when researchers or methods reduce barriers to

research participation, institutional review boards have restricted active research participation by participants with ID (McDonald, Keys, & Henry, 2008). Multiple barriers have resulted in an absent voice of people with ID in the research process, their subjective experiences uninvited into the academic discussion (Jurkowski, 2008; Moore, Melchior, & Davis, 2008; Paiewonsky, 2011). This exclusion is evident throughout the literature. Sometimes, however, people with disabilities were included in the research process.

### *Reasons for Including Voices of Individuals with Intellectual Disability*

If knowledge translates to wellness, it is practical to include, as knowledge makers, people with ID. Knowledge production is a resource, and as such, it is an indicator of marginalization. Members of dominant cultures, whether wealthy, educated, white, or nondisabled, are more likely to create knowledge (Rappaport, 1995). Invitations to participate in knowledge production are evidence of power differentials and simultaneously a way to increase parity. For example, Morningstar, et al (2010) using the Adult Trait Hope scale (Snyder, et al., 1991) as a measure of capacity for decision making, found that students with ID transitioning into postsecondary programs felt more empowered and in control of their lives when they had confidence in their decision-making abilities. Including people with ID in the research process is an expression of trust in their decision-making expertise. When invited to actively contribute to research, a group of participants with ID were shown to gain a sense of empowerment as well as skills for self-advocacy during the research process (Conder, Milner & Mirfin-Veitch, 2011). Similarly, a group of 16 adult advocates with intellectual disabilities, after participating in the research process, described feeling proud and having a sense of accomplishment (Kramer, Kramer, Garcia-Iriarte, & Hammel, 2011).

These perceptions were interpreted by co-researchers as an increased sense of empowerment. The same group of self-advocates became more efficacious of their abilities to control their advocacy planning meetings.

In each described case, participation in the research process, in any capacity, resulted in descriptions of empowerment and control. Inclusion in research processes contributed to psychological wellness. Opportunities for knowledge production were also indirectly related to wellness. By sharing their voices, people with ID reinvest in their wellness by improving interventions, programs, organizations, and agencies committed to serving people with ID. Sample (1996) included people with developmental disabilities in the construction and implementation of an evaluation to improve work and leisure. Others invited Latinos with intellectual disabilities to share their knowledge to develop better health promotion programs for people with ID (Jurkowski, 2008; Jurkowski, Hammel & Rivera, 2009). In the college environment, students with ID evaluated their college experiences and provided recommendations on how to improve college experiences for students with ID (Paiewonsky, 2011). Students also provided advice to new college students with ID on how to maximize the benefits of college experiences.

Each study reflects the importance of partnerships with stakeholders with ID so that better programs are built and decisions made that respond to the needs of individuals with ID. The proposed study seeks to engage SWID through photo elicitation and semi-structured interviews. However, in order to justify the use of photovoice techniques, it is useful to review strengths and limitations of some methods used in research with people with ID.

### *Surveys and Intellectual Disability*

Surveying people with ID has many of the same benefits as surveying any other population. Relationships between constructs can be analyzed and results can be compared with other groups exposed to common items and procedures. Under some circumstances, generalizations and predictions can be made, and in many cases, researchers can report a measure's reliability.

Jones (2012) surveyed adolescents with developmental and intellectual disabilities. Among other measures, she used The ARC Self-Determination Scale (Weymeyer & Kelcher, 1995), said to be best suited for individuals with mild ID, and the Self-Perception Profile (Harter, 1985). In each case, the instrument or the method of delivery was altered to meet individualized needs. Wording was adjusted for low-literacy readers or survey items were read to respondents.

In some cases, major adaptations were shown to be unnecessary. For a sample of PSE students with ID no difficulties administering surveys were reported (Morningstar, Frey, Noonan, Ng, Clavenna-Deane, ... Williams-Diehm, 2010). Item wording or survey scoring was not modified for the sample, but accommodation software was used to assure that it was accessible to participants with visual impairments.

Another survey study examining, among other constructs, self-determination, only used surveys that were reported to be both valid and reliable for students with ID; neither items nor administration was adapted for the abilities of the respondent (Wehmeyer, Palmer, Lee, Williams-Diehm., & Shogren, 2011). However, from the two self-determination measures administered to high school and middle school respondents, three of the four

surveys showed significant differences in results associated with respondents' levels of IQ. This may be an indicator that the survey was not equally accessible for all respondents, a phenomena which does not seem entirely uncommon.

Other limitations of using surveys when trying to capture knowledge from people with ID have also been reported. For example, in a New Zealand mixed-method, participatory research project, community members with ID reported that participants were interested in answering questions, but they had difficulty either understanding the questions or the 5-point Likert type scale. Similarly, Jurkowski (2007) reported that survey accuracy is greatly affected by intellectual limitations.

Even when surveys are modified and administered directly to people with ID, the participants are likely to answer in ways they think please those administering the survey. Maintaining survey fidelity may lead to respondent confusion or frustration. Standardized questionnaires have been shown to inadequately explain experiences of people with ID (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Adapting wording or scales, however, may negatively affect construct validity. Modified surveys risk doubly negative effects on response accuracy when respondents are confused or respond to items according to power differentials. Most literature on people with ID opted for either qualitative or mixed methods as alternatives to questionnaires.

### *Interviews and Intellectual Disability*

Accessing knowledge by interviewing people with ID has shown similar benefits and barriers as surveying. Two studies that sought health information from Latinos with ID described the benefits of interviews. In the first, researchers chose interviews and recalled

that it was necessary to acquire depth in the participants' health perspectives. Provided that participants had varied degrees of intellectual disability, researchers decided that in-depth interviews with all participants would provide the time and attention needed for participants to communicate their ideas (Jurkowski & Paul-Ward, 2007).

In the second iteration of the study (Jurkowski, Rivera, & Hammel, 2009), the researchers decided to facilitate focus groups instead of interviews. Reflecting on this choice, researchers suggested that one-on-one interviews best facilitated in-depth understanding of perspectives and experiences of participants with ID. Furthermore, participants with social limitations were unable to participate in any group-based knowledge construction exercises. As a result, researchers decided that interviews were more accessible to all participants (Jurkowski, Rivera, & Hammel, 2009).

Despite the reported successes of interviews with people with ID, Finlay & Lyons (2002) reflected that interview questions were often seen as a barrier to sharing experiential knowledge. In such situations, researchers did not reduce the complexity of questions to accommodate participants' limitations in vocabulary and memory. Longer questions or questions seeking information on abstract concepts lost meaning for individuals with ID. Therefore, it was advised, as with surveys, to keep questions as short and concrete as possible.

### *Focus Groups and Intellectual Disability*

Like those described by Jurkowski, Rivera, and Hammel (2009), focus group problems were also identified by Kaehne and O'Connell (2010). To reduce barriers to focus group participation, focus groups were modified in two ways. First, games were used as a

way to facilitate communication and turn-taking in focus groups. Second, supports who were familiar with participants facilitated focus groups and interpreted responses where speech and language difficulties existed. Advocates were able to identify rehearsed phrases that are often repeated in other contexts and that had little conceptual relevance to questions posed to the focus group. Modifying focus groups, especially with the presence of an advocate, is also risky. Advocates risk removing the agency and voice from people with ID. Using advocates as interpreters in focus groups reinforced pervasive social assumptions that people with ID are incompetent (Kaehne & O'Connell, 2010). And, similar to holding conversation through a translator, the message which the researcher receives from the advocate may not accurately represent the message that was sent by the participant. Also, the advocate was in a position to influence the person with ID and the knowledge they shared.

Overall, Kaehne & O'Connell lay out four challenges to facilitating focus groups, two of which are relevant to the current research. First, the degree to which people with ID can address others perspectives and perpetuate a relevant and engaging dialogue varies between participants. Second, the problems that focus group advocates or facilitators cause often outweigh their benefits.

### *Life Story Books*

With digital cameras and video cameras built into a variety of mobile devices and with the pervasiveness of social media, individuals have the chance to continually build and review self-documentary. Life story books are another self-documenting method. They are a self-created account of one's life, with particular attention devoted to identity-shaping relationships and experiences (Moya, 2009). For people with intellectual disabilities, life



stories have been constructed as a method for preventing objectification. Distinct histories showing interconnections between life events and relationships mediated communication and contextualized people with ID.

Examining thoughts written into the commentary page of life books and from recordings of staff meetings, half before and half after the arrival of a new individual with ID at a community care facility, Moya (2009) examined how life books changed the ways that people with ID were talked about by care staff. Life books served as a tool for building rapport between staff and new residents. They also helped staff move away from notions of fixed identity. No longer were residents with ID ‘patients with ID’, they became siblings, children, friends, students and they were talked about as human beings with unique histories (Moya, 2009).

The main limitation of this method was, like advocates in focus groups, life stories were biographical rather than autobiographical. Photographers, biographers, and other life story creators have a role in formulating the book’s rhetoric and, thus, identity. Training can be provided to increase the choice and perspective of the life book’s subject, but a distinct power differential is constructed between those who produce images and words and those who are the subjects of them. A method for increasing participation can quickly regress into a method that removes one’s agency and ability to define their life.

### *Photovoice*

Photovoice is a series of procedures for eliciting and amplifying the experiences of traditionally marginalized populations (Wang & Burris, 1997). After developing skills in ethical and technical photography, participants photograph every day, lived experiences

embedded within physical and social environments. Participants then narrow a collection of photographs to a salient few and with other members of their communities discuss the affective and rhetorical significance of the photographs.

Most often, community discussions are focus groups, facilitated by a researcher equipped with semi-structured, probing questions. Photographs serve as an instrument for sharing subjective experiences but they also help elicit conversation. In describing the importance of photographs, participants share experiences and the contexts of their daily lives. The last stage of the process is that photographs, which are democratically voted as being most representative of the groups' experiences, are displayed to share knowledge with decision makers that have the power or resources to enact change in the participants' lives.

Few studies have used the photovoice process to reveal more about the subjective experiences of individuals with ID. One was a study that provided cameras for 16 mothers with intellectual disabilities (Booth & Booth, 2003). The researchers discovered benefits and problems of using photovoice. Photography seemed particularly suited for individuals with ID because pictures provided a medium of expression for individuals with communication difficulties- images, in part, tell stories. Further, photography concretized thoughts, emotions, and concerns that usually require complex and descriptive vocabulary to accurately communicate. Booth and Booth (2003) noted that through photography individuals had the choice to collect data most salient to their experience. By trusting participants' competencies, their position is validated. Lastly, participation in a group project motivated participants and helped construct a critical consciousness.

Still, this project was presented with a variety of difficulties. Participants needed reminders to take pictures; most did not take enough pictures to use all the film in their disposable cameras. Mothers forgot to bring cameras to researchers so that film could be developed. Participant attrition forced the study to proceed with photograph discussions in one-on-one interviews instead of in focus groups. The last decision created dissemination; many participants refused to post their photographs to online galleries where they could be viewed by family, community, support staff and policy makers. This barrier made it more difficult to enact changes to improve the lives of mothers with ID.

The three other photovoice studies (Jurkowski, 2007; Jurkowski & Paul-Ward, 2008; Jurkowski, Rivera & Hammel, 2009) shared the same principle investigator, Jurkowski, and the same target population: adult Latinos with ID. The authors recorded similar lessons across studies. These lessons have largely guided the proposed photovoice processes for the current study. Here, the Jurkowski studies will be collapsed and reported simultaneously.

Across these studies, individuals with ID were active participants in defining their health environments and creating data which represented their health experiences. This study avoided tenuous claims of more authentic, more real or 'truer' data produced in photovoice projects, and focused on representative photographs of lived experiences and environments.

Researchers reported that participants became increasingly proud and confident during the photovoice experience (Jurkowski, 2007). Each printed photograph rewarded and motivated participants to continue to compile pictures. Printed pictures were placed into a scrapbook similar to Moya's (2009) life story books. With the scrapbooks participants shared

important health issues and engaged, in one-on-one encounters or at town hall meetings, those who made health decisions that affected the participants' wellness.

The photographs and scrapbooks were said to increase perceptions of ownership in the research process, which also increased the engagement and motivation that are often not reported with other methodological techniques employed with populations with ID. Further, photography was described as beneficial because it showed a world where researchers were not present, suggesting that photographs and the conversations they elicited were more representative than the data which emerges from non-photo elicitation methods, like standard interviews or focus groups. Finally, photographs were beneficial for engaging nonreaders or participants with low literacy, allowing the population to record and reflect their perspectives.

The Jurkowski studies do, however, present challenges that could exclude some individuals with cognitive impairments, the population photovoice is well suited to serve. As with all other methods reported, photovoice tends to exclude participants who are entirely nonverbal or socially limited. Photographs can represent some experiences but are not fully suited to replace words that participants use to describe their motivations for capturing specific subjects or meanings embedded within pictures. Data collection through photovoice was also more time consuming and required technical and ethical training. Jurkowski (2007), for example, described a participant who was never able to share a photograph because the camera's flash settings, as well as contexts when using a flash was needed, were never fully understood. Also, participants that do not understand the purposes of photograph release forms or consent forms unintentionally endanger themselves or others. The present study

benefited from lessons presented in the literature. By developing more extensive training programs suited to individual competencies, many problems noted in past research were addressed, though not entirely prevented.

### *Combining Methods*

To this point, presented literature described the ways that people with ID transmitted and collected data. Methods that allow for participation were flexible as well as accessible. Principles of Universal Design (UD) describe ways to increase access to physical or academic environments. Some primary tenants of UD are flexibility of use and multiple media of communication (Scott, McGuire, & Shaw, 2003). Paiewonsky (2011) constructed a strongly UD compliant research project by inviting college students with varying degrees of intellectual disability to share their college experiences in mediums best suiting their strengths. A website was created for participants to upload digital pictures, video, audio and written word to share personal narratives (Paiewonsky, 2011).

In a fluid, digital space, participants were able to comment on one another's perspectives either in real time or when convenient. Commentary, like data, could be added to the storytelling application in a variety of ways that best suited individual's preferences and abilities. These methods were adopted because evidence perspectives are revealed over time (Paiewonsky, 2011). Moreover, in the multimedia, digital, storytelling projects, participants had the opportunity to build capacity. They learned how to effectively utilize digital hardware and software and develop strategies for more effective communication.

Similar to photovoice limitations, a main concern was that multimedia projects require too much time and money thus making the methods largely inaccessible to

participants and researchers with scarce time or resources to commit to such an undertaking. Paiewonsky (2011) conceded that other methods might be more cost effective and yield equally important information.

### *Analysis and Interpretation*

All literature examined to this point acknowledged that people with disabilities have valuable perspectives and insights worthy of acquiring. They also described methods for accessing experiences or opinions. For all the interest in accessing knowledge there was little emphasis placed on people with ID analyzing or interpreting the data they produced, especially when data were generated from youth or individuals with moderate or severe intellectual disabilities.

None of the literature outlined instances where individuals with ID provided any feedback to quantitative data. Often qualitative studies, reporting primary participants as individuals with ID, did not include those individuals in interpretation or validation of data. Ward & Trigler (2001) warned that people with ID invited to participate in analysis and interpretation of data had a hard time summarizing group experiences in ways that were different from personal experiences. Most often, individuals with ID did not analyze raw data. Themes were instead interpreted by experienced colleagues (Abbott & McConkey, 2006), people who were familiar with the participants with ID (Johnson, Douglas, Bigby & Iacono, 2012) or by the study's research team (Grandisson, Tetreault & Freeman, 2012).

Jurkowski and Paul-Ward (2007), on the other hand, reconvened photovoice participants in a 'member-check' focus group to discuss the validity of the themes produced from individualized interviews. However, the study never confirmed if the themes were

deemed valid by the participants with ID. Another group had the themes validated by a focus group of adults with ID, but it was not made clear if the adults with ID were the same ones who participated in the study (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Another study collected data from 14 young adults with ID, but less than one-third of the participants were invited to check interview transcripts for accuracy (Hall, 2009). Finally, one study (Jurkowski, 2008) showed more confidence in participants with ID and invited them to verify findings. Prioritized themes were entered into a final report and discussed at a town hall meeting. In this dissertation research, Students were given a chance to confirm during an interview whether or not their main ideas had been captured in previous interviews. When all interviews were completed, paid Supports were used to validate and challenge thematic categories created from Students' social experiences.

The prototypical study for inviting people with ID to interpret and analyze data made the research processes more accessible. Working with 16 members of a community-based self-advocacy organization, researchers developed a 'Who Did What' checklist where participants could monitor whether researchers, participants or a combination of both directed elements of advocacy meetings (Kramer, Kramer, Garcia-Iriarte, & Hammell, 2011). The checklist was comprised of categories like "Who thinks of items to put on the agenda?" or "Who introduces new topics at the meeting?". After 17 meetings, over the course of nearly two years, researchers used pictures and bar graphs to display data for each item on the checklist. Then, participants were asked to examine the frequency of who led each checklist item over the course of the study. The participants with ID were able to identify that

they had guided two-thirds of meeting elements. Participants provided qualitative interpretations explaining why each meeting was or was not led by participants.

From this process, participants reported feeling proud of their accomplishments and becoming increasingly aware of their capacities for research and advocacy. Moreover, the study introduced strategies for making data analysis and interpretation an inclusive process for people with ID. However, in the process participants did not play a role analyzing or validating their qualitative feedback. Similar to focus group limitations, some participants were unable to participate in data interpretation because the process relied on verbal communication. Therefore, members who communicated non-verbally did not have an opportunity to contribute to the analysis. Nonetheless, this study showed that with modifications for literacy and numeracy, people with ID can actively participate in data analysis and interpretation.

### **Social Inclusion**

Across each of the previously discussed studies and methods people with ID were extended varying degrees of participation in the research process. Despite the different appearances, 'inclusion' was a common thread. However, academic literature lacked a consensus of the terms 'inclusion' or 'social inclusion'. Professionals have yet to agree upon a shared conceptualization or operationalization for social inclusion, not just in the research process, but across all elements and experiences of daily life.

Martin and Cobigo (2011) described an academic community that used, interchangeably, concepts like 'participation', 'integration', and 'social inclusion'. Operationalizing the terms was similarly challenging. In one case, survey data from 1341



adults with intellectual disability simultaneously confirmed and denied participants social inclusion depending on how data were interpreted (Martin & Cobigo, 2011). Cummins & Lau (2003) noted that objective measures of social inclusion, such as the frequency of participation in social activities, were inadequate at determining one's socially inclusion, and report nothing on the quality of social experiences. Individual's subjective social experiences were deemed more adequate for capturing quality of inclusion. A single best way for capturing social inclusion is as difficult as building consensus for social inclusion definitions, and it remains an ill-defined construct.

Moving forward, this study will review the various descriptions of social inclusion. Through descriptions of social inclusion and its antitheses, researchers can better understand the elusive construct. Predictors, covariants, and outcomes of social inclusions have been scarcely documented but related variables will be reviewed. There will also be descriptions of contexts in which social inclusion was likely to emerge as well as shared perspectives on barriers and benefits for social inclusion. To remain consistent, each study under review targeted social inclusion for individuals with intellectual disabilities. Where possible, reviewed literature emphasized the roles played by individuals with ID in conceptualizing and describing social inclusion.

### *Defining Social Inclusion*

Abbott & McConkey (2006) suggested that social inclusion, as a construct, is not inclusive. The social inclusion for people with ID was considered less extensive than the social inclusion for the rest of society. Increased social participation in community activities and broader social networks were the primary requirements for one with ID to be considered

socially included. But, for those without ID, there was an expectation of economic participation and socially valued roles, such as that of an employee or a parent (Abbott & Mcconkey, 2006; Burchardt, Le Grand & Piachaud, 2002). Because people with ID were viewed as less socially competent, the expectations for their social inclusion have also been less.

In Scotland, the department of health noted differing expectations for social inclusion and created four principles to catalyze social inclusion for people with ID. The four principles were rights, independence, choice and control, and suggested ways to enact these principles were offering more paid employment, independent living and community participation (Hall, 2010). Principles and strategies were meant to reduce gaps between expectations of social inclusion for people with and without ID. Eliminating the gap, however, was done by moving the ‘abnormal’ towards the practices of the ‘normal’, creating a victim blaming rhetoric: social inclusion was the sole responsibility of individuals with ID. Furthermore, social inclusion was not necessarily found in the workplace, neighborhoods, or through community activities, and sometimes the construct was found in places thought to be exclusionary, like long-term care facilities and sheltered workshops (Hall, 2004, 2005, 2010).

Subjective experience provided an alternative perspective on social inclusion. Beyond expectations and spaces, Hall (2010) proposed that a sense of belonging, attachment and personal value, along with a perception of insidership and closeness built social inclusion and dismantled exclusive structures. The absence of loneliness has been described as having those meaningful and rewarding interpersonal experiences (McVilly, Sancliff, Parmenter, & Burton-Smith, 2006).

Mactavish, Mahon & Lutfiyya (2000) synthesized the voices of people with ID to construct a definition of social inclusion that emphasized a sense of belonging and opportunities to enact valued social roles. In a phenomenological investigation of social inclusion for young adults with ID, social inclusion was defined as “being involved in activities, developing and maintaining reciprocal relationships, and having a sense of belonging” (Hall, 2009b). The definition Hall used for reciprocal relationships was reduced from Ware, Hopper, Tugenberg, Dickey and Fisher’s (2007) description and failed to explain the relationships’ reciprocal nature stating only that they are relationships that are enjoyable and assist one in accessing resources. Unlike Lemon and Lemon (2003) who argued that people with ID could make contributions to society and that reciprocity, or interdependence as they called it, was crucial for social inclusion, Hall never described the ways that people with ID meets others’ needs. Conversely, Hall (2009a) offers a fairly robust description of a sense of belonging, defined by individuals with ID as being accepted by others, being seen as an individual instead of a diagnosis, having positive interactions, and not being marginalized or bullied.

Sense of belonging has long been identified as one of four factors comprising the psychological sense of community construct (Chavis, 1986). Psychological sense of community was proposed as a high quality subjective measure of community inclusion (Cummins & Lau, 2003). However, there were exclusionary trappings associated with sense of community, which was said to be best nourished by those sharing a common identity, implying that community, for people with ID, was best established with others who have been identified as intellectually disabled. This assumption, of course, chokes social networks

and congregates individuals with ID into “asylums without walls” (Dear & Wolch, 1987).

While sense of community seems a subjective necessity for people with ID, social inclusion, meeting Hall’s (2009) first standard, requires involvement and participation.

### *Exposure, Spatial Integration, and Social Exclusion*

There is value in describing elements and context that define and create social inclusion. To adequately define the construct it is useful to describe terms that are similar but not interchangeable. Describing conditions that define the absence of social inclusion are also useful. To further distill conceptualizations of social inclusion, efforts have been made to describe differences between inclusion and terms like exposure, integration, and exclusion.

Exposure and integration are instances where people with intellectual disabilities are physically included in a variety of social spaces. This may include recreational activities like bowling, economic activities like shopping, as well as religious and educational opportunities to share space with people without intellectual disabilities. The benefits of physical integration are that people with ID expand their experiences and explore novel spaces. But, as Cummins and Lau (2003) described, the long-term benefits of participation in social spaces increase visibility for people with ID and with it the likelihood that community resources will flow to increasingly visible groups. Secondly, the more exposure the public has with people with ID, general attitudes and public acceptance are also likely to increase (May, 2012).

Otherwise, exposure and integration have been viewed as tokenism. People with ID have gained access without acceptance and remain socially excluded in inclusive environments. Employment, Hall (2004) explained, provides economic and spatial inclusion

but counterbalances any potential benefits through discrimination and isolation. Poor relationships were common with co-workers and employers' demands for productivity allowed for few differences in ability between employees. Again, the emphasis was placed on individuals' deficits instead of strengths and contributions. As long as discrimination and abjection are more common in work, housing, and the community, and little attention is paid to histories, geographies, cultures and economies that create exclusionary atmospheres, social inclusion is not tenable, and people with ID will be further removed from the social and economic majority. More simply put, a wide partition separating spatial inclusion and equitable experiences in social spaces was reported.

Social exclusion has been described as a creation of unequal power relations that exist throughout society, including but not limited to institutions, markets and communities (Moore, Melchior, & Davis, 2008). In addition, Wiesel (2009) targeted private market mechanisms as an epicenter of exclusion, instead of any overt, community-driven opposition to the inclusion of people with ID. Social exclusion was viewed as a lack of recognition of one's worth that resulted from people with ID being viewed as passive, unskilled and burdensome beneficiaries of society's time, energy and money. Where interdependence and mutual affiliation did not exist or was unrecognized, community also did not exist (Wiesel, 2009), or where community did exist, people with ID were not part of it (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Moore, Melchior, and Davis (2008) extended this argument by integrating anemic social networks as a hallmark of exclusion. People with ID participated in social ties predominantly with care staff and family, and social networks were commonly not too expansive (Walsh, 2002). McVilly, Stancliffe, Parmenter, & Burton-

Smith (2006) described perceptions of loneliness that manifested from deficient social networks and social isolation- and people with ID often experienced both. Therefore, one required element of social inclusion is a more robust social network where one is tied to a variety of people within their community and potentially beyond. Social inclusion was characterized by ties with others, activities in social spaces, and perceptions of belonging.

In summary, social exclusion is commonly coupled with physical integration in mainstream environments. Discrimination and the lack of control limited social networks and social opportunities and, thus promoted social exclusion. Policies have failed to challenge exclusionary institutional, organizational, and community cultures (England, 2003; Hall, 2010). Under these scenarios the discordance between the individual and the setting were paramount; similarities were underemphasized and social inclusion as a reality for people with ID was increasingly unattainable.

### *Social Contexts*

Where social networks were small, it is necessary to expand the quality and quantity of social ties that promote social inclusion. Connection to a broad social network supported people with ID in meeting their emotional and practical needs (McVilly, et. al., 2006). Moreover, this study showed that individuals with ID were most lonely, or socially excluded, when they relied on the bulk of their social interaction to come from one significant other. Those who self-reported social inclusion perceived themselves to be part of a reliable network comprised of many people (McVilly, et. al., 2006). Social networks that met ones needs and connected one to many significant others allowed for more participation in

community activities, further influencing perceived life satisfaction of people with ID (Miller & Chan, 2008).

Other socio-cultural factors that influenced, beyond breadth of social network, were examined through social inclusion in sporting leagues (Grandisson, Tetreault, & Freeman, 2012). When coaches had a greater knowledge of ID, a more inclusive team atmosphere was created. Similarly, exposure to people with ID altered college students' attitudes. Compared with political science majors, special education students, who had attained more knowledge about people with disabilities, had more positive attitudes towards people with ID (Rice, 2009). Insofar as knowledge is generated by contact, previous exposure to people with ID has been related to more favorable attitudes towards inclusion of students with ID in the college environment (Westling, Kelley, Cain, & Prohn, in press) and among members of Canadian communities (Ouellette-Kuntz, Burge, Brown, & Arsenault, 2010).

Attitudes play a primary role in social inclusion. Literature shows the ways positive perceptions of people with ID can change with exposure and how positive attitudes can lead to more opportunity. For people with ID to be actively included in research, researchers and Institutional Review Board members must have positive attitudes about the abilities of individuals with ID to make their own choices (McDonald, Keys, & Henry, 2008). Positive attitudes of politicians 'in power' ensured that people with ID were acknowledged and valued in the political arena (Frawley & Bigby, 2011). Middle school students who had more contact with students with ID in contexts where competencies could be observed were more likely to have attitudes that approved of the inclusion of students with ID in middle school classrooms (Siperstein, Parker, Bardon, & Widaman, K. (2007). College students who were

enrolled in college courses with students with ID had more favorable views about abilities of students with ID (Griffin, Summer, McMillan, Day, & Hodapp, 2012). Interventions to increase awareness about people with ID have also shown to effectively increase positive attitudes towards the inclusion of people with ID (Rillotta & Nettelbeck, 2007). Overall, positive attitudes, whether constructed through values, exposure or knowledge, have been related to more socially inclusive opportunities.

### *Place, Space, and Social Inclusion*

Some places are more inclusive than others and the factors promoting inclusion are nuanced. In Dutch neighborhoods, when a person's intellectual disability was perceived as less severe they were more socially welcomed as neighbor (Dijker, van Alphen, Bos, van den Borne, & Curfs, 2011). However, distinctions were made between friends and neighbors and of the two categories, individuals with ID were in the latter. Workplaces, especially sheltered workshops (Lemon & Lemon, 2003), were also deemed to not facilitate social inclusion (Butcher & Wilton, 2008). In class environments, elementary through post-secondary schools, where academic material was made more accessible, students of all abilities appeared competent and were more accepted by classmates and instructors (Scott, McGuire, & Shaw, 2003). Political environments were also made more inclusive and open to people with ID when accommodations made information more accessible for people of all cognitive abilities (Fawley & Bigby, 2011). Bigby and Wiesel (2011) introduced the concept of 'encounter', the fleeting exchanges with strangers while moving through spaces, as opportunities for people with ID to not be defined by their disabilities, and thus increasing, if just for a brief period, social inclusion. On public transportation, for example, people with ID



were viewed as users of public transport before they were defined by disability alone. People with ID became group members based on shared activity (Bigby & Wiesel, 2011). Finally, Grigal & Hart (2010) described several types of PSE models. One model was defined by inclusion. In such a model student strengths and interests guided their postsecondary experiences. Flexible schedules allowed students with ID to independently participate in the broad social milieu available in their campus communities, and student aids facilitated participation in a variety of college or university settings. However, individuals without disabilities can be assets or barriers to social inclusion.

#### *Supports, Paraprofessionals, Staff, and Social Inclusion*

The need for support varies greatly for people with ID depending on abilities to meet environmental demands. Some individuals become entirely independent, managing their own finances, living alone and gaining some type of competitive employment. Others, primarily individuals with moderate or severe disabilities, need support for many or all activities in their daily lives. Regardless of ability, some degree of support provided through people, procedures, or assistive technology, is needed at school, work and other spheres of daily living.

People serving in support positions are likely to be women but display variability in age, ethnicity, education and training. They also work with people with ID in a variety of environments. Some may be employees at long-term care facilities or group homes and others may be job coaches or same-aged peers in an educational environment. Their impact on the social inclusion of people with ID also varies. Some are catalysts for social inclusion

and others serve as buffers to natural or ‘normalized’ social experiences. The instances where supportive others have been barriers to social inclusion will be represented first.

When people with ID began to be removed from asylums and institutions they began to find housing opportunities in communities. Community facilities were shared by people with ID and live-in staff. A crucial skill for staff was learning to balance support without interfering in social relationships. People sharing social environments, such as neighborhoods, with people with ID and residential staff members, were confused by staff roles (van Alphen, Dijker, van den Borne, & Curfs, 2010). Neighbors were unsure if they could directly interact with residents with ID or if they needed to approach staff first. Social confusion and hesitation resulted in a decreased likelihood that interaction would occur. Neighbors also misunderstood their direct relationships with staff. Staff were present often enough to be familiar with neighbors, but when the staff did not acknowledge neighbors with a friendly acknowledgement, neighbors felt ‘snubbed’ (van Alphen, Dijker, van den Borne, & Curfs, 2010). Feelings of rejection decreased neighbors’ favorable attitudes towards staff and the residents with ID for whom they cared. A similar study (Dijker, van Alphen, Bos, van den Borne, & Curfs, 2011) found that neighbors anxiously anticipated contact with their neighbors with developmental disabilities. They wanted staff members to provide advice on how to interact with residents. If neighbors perceived staff as burdened or disinterested in answering pre-contact questions, the neighbors did not interact well with residents at later stages of contact (Dijker, van Alphen, Bos, van den Borne, & Curfs, 2011).

Staff can similarly obstruct social relationships in the school environment. Students with ID, who were supported in high school by a paraprofessional, found that students saw

their paraprofessionals as mother-like figures (Broer, Doyle, & Giangreco, 2005).

Paraprofessionals were often middle-aged women. Students reported having a diminished status because they received continuous care from a person who was an atypical character in the high school environment. Students felt that their peers would not want their interactions overheard or mediated by an older, motherly figure. Paraprofessionals' interference in what would be normally occurring social interaction contributed to students' perceptions of isolation and not belonging by students with ID.

In other non-school contexts staff caretakers served as key figures in perceptions of social inclusion by people with ID. For people with severe ID, support staff were primary partners in two types of meaningful social interaction: having fun and hanging out (Johnson, Douglas, Bigby, & Iacono, 2012). Because of the importance of staff for social wellness, it was viewed as a necessity to train staff to monitor health of individuals with ID and also engage in meaningful social interaction.

Staff can also assist people with ID in attaining the social and communication skills necessary for increased social inclusion (Bigby & Wiesel, 2011). Thorn, Pitman, Myers and Slaughter (2009) showed that staff enhanced existing social relationships and created more opportunities for building future social relationships by teaching functional skills such as dining etiquette, safety, and social interaction. They also found that better educated staff better facilitated social integration between people with ID and their non-disabled community members. Finally, as much as paraprofessionals working with students with ID in high school were seen as a barrier to social inclusion, they were also deemed as a social asset. 'Care professional' and 'friend' were often not mutually exclusive terms. It is a

delicate balance, but it is optimal, in some environments, when help staff are also friends. Students even reported some circumstances where matronly paraprofessionals were friends—like when fending off bullies and educating when school teachers would not (Broer, Doyle & Giangreco, 2005). Help staff always benefited from training. It was recommended, that paraprofessionals learn how to facilitate social inclusion while continuing to provide friendly companionship.

#### *Social Inclusion as Described by People with ID*

The need for training paraprofessionals to expand their roles and facilitate social inclusion came directly from student feedback (Broer, Doyle, & Giangreco, 2005), and if training were built on this feedback school experiences could improve for many students with ID. Likewise, to better understand social inclusion and the elements that facilitate and obstruct it, researchers have gone to the subjective experiences of people with ID. Abbott and McConkey (2006) got feedback from 68 adults with ID from Ireland. These individuals primarily described social inclusion through four themes: talking to people, being accepted, using community facilities, and opportunities. From these themes, social inclusion occurred when one meets new people and talks with others from the community. It also occurred when people were treated well and not singled out for their disabilities. It occurred when one had access to activities, services, transportation and other community resources and when opportunity to access the community was not restricted by ones location or support.

Abbot and McConkey (2006) also reported the four main barriers to social inclusion. Many barriers were captured in the description of social inclusion and included personal skills, staff, the community, and one's living arrangements. People were more socially

excluded when they did not have the confidence to pursue interaction or knowledge of where to go to meet others. Staff, as mentioned earlier, served as barriers by restricting independence and treating people with ID as children. The community was a barrier when community members had negative attitudes towards people with ID or when it did not have the social and physical infrastructure to meet ones needs. Lastly, the location of home was isolating if it was located further away from community resources and when transport to those resources ran infrequently or was expensive. When people with ID were able to define social inclusion and the barriers to it, solutions were proposed, and included ideas such as functional skills training, staff making better efforts to listen, better educating citizens about intellectual disability, and access to public transport.

In a similar study, 14 American adults with ID shared their subjective, everyday descriptions of social inclusion and social exclusion (Hall, 2009). Seven themes describing experiences of social inclusion emerged. The first was living accommodations and transportation. People felt included when accommodations and transportation allowed them to access social activities, resources, and social networks. Working increased control over finances and also provided alternative social opportunities and workplace interactions. Being involved and staying involved in social, interest, and religious groups increased perceptions of social inclusion. Having quality interactions and relationships with many community members, family members, and friends was critical. Staying involved and interacting with others helped participants develop a sense of belonging. Social roles associated with responsibility, sharing one's voice, and radiating one's individuality were crucial for social inclusion. Finally, miscellaneous factors like communication abilities and personal finances

completed descriptions of social inclusion. Needless to say, the absence of any of these elements contributed to social isolation. More unmet elements equated to more perceived social isolation. Hall (2009) included a table, which is recreated below (see Table 1), and describes situations when individuals felt included or excluded.

Table 2.1

*Experiences of Social Inclusion*

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<p><b>Young adults with ID experienced limited social inclusion when:</b></p> <ul style="list-style-type: none"><li>• They could not take the city bus in the evenings or on weekends.</li><li>• They did not have enough money to participate in activities or live on their own.</li><li>• They did not have skills or assistance to plan social events with their friends.</li><li>• They worked part-time and did not spend time with coworkers.</li><li>• They spent most of their free time with staff or parents.</li><li>• Their friends and family left them out of activities and conversations.</li><li>• People made fun of them, called them names and looked at them differently.</li><li>• Community members avoided or ignored them.</li></ul> <p><b>Young adults with ID experienced greater social inclusion when:</b></p> <ul style="list-style-type: none"><li>• They learned how to problem-solve, budget money, plan meals and access transportation.</li><li>• Service providers were available to provide frequent transportation.</li><li>• Parents and service providers identified activities to attend.</li><li>• Others organized and drove them to get-togethers with friends.</li><li>• Service providers helped them study for college, learn job skills, and find employment.</li><li>• They spent time with coworkers on break or outside of work.</li><li>• They were involved in sports and social groups for people with disabilities.</li><li>• Community members talked to them and treated them similar to others.</li><li>• They were in advocacy groups and given opportunities to self-advocate.</li></ul>
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Two groups of people with ID from different countries and different living arrangements described similar social experiences. Desired independence was more salient for those living in group homes or supported living facilities. For both groups, social

interaction and relationships were necessary for perceptions of inclusion, but also as a vehicle for involvement in community activities. Being accepted or having a sense of belonging was also a common theme across groups, and was described as present with positive interaction and diminished when left out and ignored (Abbott & McConkey, 2006; Hall, 2009). A sense of belonging was also a repeated theme in social inclusion literature (Mactavish, Mahon & Lutfiyya, 2000; Cummins & Lau, 2003; Hall, 2010). Transportation was also a key element for each group to feel socially included. Access to activities and social spaces required transport and taking public transportation also created opportunity for social encounters (Bigby & Wiesel, 2011). Similar barriers were also accounted for across studies, including a lack of personal and social skills necessary to create and sustain social opportunities, the location of living accommodations, and the community's attitudes towards people with ID. When barriers to social inclusion have been mitigated, silenced or removed, individuals with ID attain positive benefits.

#### *Correlates and Outcomes of Social Inclusion*

Social inclusion is a matter of equitable treatment and social justice. Where similar opportunities are extended to all populations, there are beneficial associations and outcomes related to social inclusion. Jones (2012), for instance, found a significant correlation ( $r=.52$ ,  $p<.01$ ) between perceptions of self-worth and an element of social inclusion: a sense of belonging. Miller and Chan (2008) found that individuals who sought, nourished, and maintained prolonged social interactions with others were likely to have higher levels of life-satisfaction ( $\beta = .35$ ,  $t(55)= 2.76$ ,  $p<.01$ ). Increased functional skills also enhanced social

inclusion and community participation when measured over time, even at maintenance stages (Thorn, et. al., 2009).

Having supportive social relationships was also a significant predictor of life-satisfaction ( $\beta = .44$ ,  $t(81) = 3.78$ ,  $p < .001$ ; Miller and Chan, 2008). Supportive social relationships were significant correlates or predictors of quality of life (Campo, 1997; Lunsy & Benson, 2001; Schalock & Keith, 1993; Bramston, 2005 as cited in Miller & Chan, 2008). Also, addressing the differences between spatial and social inclusion, subjective well-being was associated with social inclusion but not physical integration (Burleigh, Faber, and Gillard, 1998). In addition, people with ID who had rich social networks experienced less loneliness than those who had an unmet desire for a supportive social network (McVilly, et. al., 2006).

A few studies also reported the physical health benefits of social inclusion. By being included in recreational sports and by teammates and coaches alike, adolescents with ID showed health improvements and development in motor skills (Grandisson, Tetreault, & Freeman, 2012). Further, people with ID described a link between feeling good physically and having an active social network (Jurkowski, Rivera & Hammel, 2009), and they were more interested in improving their physical health when exercise activities were social (Jurkowski, Rivera & Hammel, 2009). The benefits of socially including individuals with ID also extends to others without disabilities.

#### *Benefits of Inclusion for Others*

Socially including people with disabilities had positive effects for others who participated in social contexts. Parents were shown to feel more pride in included children



and reported better relationships with their child with ID (Grandisson, Tetreault, & Freeman, 2012). Some peers gained better awareness and comfort with differences (Grandisson, Tetreault, & Freeman, 2012) while others, in the college environment, who shared a class with students with ID, reported less anxiety towards difference and increased comfort with disability (Carroll, Petroff & Blumberg, 2009). The college classmates were pre-service teachers who reported gaining valuable vocational training applying pedagogical concepts to their peers with disabilities (Carroll, Petroff & Blumberg, 2009). Other college students, in addition to feeling better prepared for future jobs, reported increases in positive affect that resulted from social interactions with students with ID (Westling, Kelley, Cain, Prohn, 2013). Also, care workers for people with severe disabilities reported increases in enjoyment at work when they shared meaningful social interactions with the population they served (Johnson, Douglas, Bigby, & Iacono, 2012). Lastly, Prohn (2013) reported that when students with ID felt included in and empowered by their environments they were more likely to improve their communities through fundraising, advocating, and volunteering. If social inclusion requires reciprocal relationships, then socially included individuals with ID should meet social partners' needs while benefitting themselves.

### *Literature Summary*

The review of literature described the ways people with ID have been included in knowledge production and research processes. Overwhelmingly, qualitative studies were conducted because surveys have shown to be inaccessible and they did poor jobs at reporting experiences of people with ID. Many objective measures, such as the frequency of visits to public places, were described as insufficient at capturing social inclusion. Subjective,

qualitative research actively engaged participants in the research process and provided opportunities for sharing salient daily experiences. Photovoice was shown to be particularly helpful in assisting communication of subjective experiences. Photographs concretized abstract feelings and helped people with limited social and communication abilities highlight important life experiences. Describing pictures and being involved in data collection increased the confidence, capacities and senses of ownership for photovoice participants with ID. And, despite social inclusion's lack of clarity, photovoice has not been used by people with ID to further describe the construct. Furthermore, social inclusion was described by people with ID in community contexts, but never by people with ID living on college campuses.

The literature also repeatedly described the role of supportive workers in the lives of people with ID. These employees were major players in the way people with ID described social inclusion. Sometimes support staff were assets and sometimes they were barriers to social participation. In most cases, there was recognition that support staff was familiar with the quality and quantity of their client's social networks. Therefore, it makes sense to include Support perspectives in research to better understand social inclusion of students with ID in college settings.

### **Research design**

Social inclusion is relational—two or more people are required for individuals to be included in something. Even if inclusion is believed or perceived, the perceptions require a referent person, group or groups. Because social experiences require, at minimum, the idea of

a social ‘other’, Student’s social experiences were described by two groups, Students and Supports, using multiple methods. First, Supports participated in a one-time internet survey to share beliefs about Student social experiences. The questionnaire results served as a general appraisal of Students’ social experiences. Next, Students had the opportunity to add context, personal narrative, and meaning, bringing new dimensions to Supports’ questionnaire results. Students participated in four photovoice interviews over four consecutive weeks. One month of student data collection and interviews created time for students to mature as participant-researchers and grow more comfortable with photovoice processes. In the final stage, three paid-Support focus groups were administered. Paid supports described their relationship with Students and their observations of Student social experiences on campus. Focus groups served as theoretical samples, meant for confirming or adding to Student observations of social experiences.

Table 2.2

*Data Collection*

Data Collection Dates	Method	Purposive Sample Groups	Sample size (purposive, nonrandom)
October, 2012	Internet questionnaire	Paid & non-paid Supports	74
March & April, 2013	23 photovoice interviews	Students	6
April, 2013	3 focus groups	Paid Supports	15

Social environments are in constant flux. Friends and groups change, networks expand and contract, and people's motivation to interact with others varies with experiences and context. The design invited contributions from two groups with intimate knowledge of the phenomena in question with Students' personal, lived experiences prioritized. Data interpretation places more value on Student descriptions with Support perspectives as important but supplementary.

### **Research Questions and Hypotheses**

Again, for the purposes of clarity, 'Students' were college students with intellectual disability who served as participant-researchers in the study. 'Supports' were typically developing peers, enrolled in the same college that provided assistance to help Students meet college participation's demands. Both parties' descriptions of Students' social experiences were organized and interpreted to answer three research questions:

*Research Question 1:* How do Students describe and explain their social experiences that occur within the campus community?

*Research Question 2:* How are Students' social experiences described and explained by Supports?

*Research Question 3:* Do Students and Supports' accounts provide sufficient evidence of Students' social inclusion?

Research question 2 was partially addressed through Support responses to an internet-based questionnaire. Measures were not implemented in intended ways, and the discriminate validity of subscales was not assumed. It was hypothesized that perceptions of Students' social support would significantly and negatively correlate with perceptions of Student loneliness. Support subscales were expected to correlate significantly and positively.

H<sub>0</sub>: R = 0, loneliness is not related to social support

H<sub>1</sub>: R > 0, loneliness is related to social support

H<sub>0</sub>: R = 0, social support subscales are not related

H<sub>2</sub>: R > 0, social support subscales are related

Supports were broken into two groups: paid and unpaid. Paid Supports had more experience aiding Students and they spent more time per week directly engaged with Students. With increased Student time, paid Supports were hypothesized to report different observations than their unpaid peers when assessing Students' social experiences. A direction of differences in loneliness and social support was not predicted because it was not clear if a better understanding of Students' social lives would lead Supports to view students as more or less included.

H<sub>0</sub>:  $\mu_{\text{paid}} = \mu_{\text{unpaid}}$

H<sub>1</sub>:  $\mu_{\text{paid}} \neq \mu_{\text{unpaid}}$

Qualitative hypotheses were secondary and utilitarian. The main purpose of administering the questionnaire was to advance the amount of available information about Students' social experiences. Secondary were quantitative measures used to understand interrelationships between measures and search for group differences, especially because focus groups were constructed of paid-supports only.

Only recently have colleges permitted students with ID to participate in college experiences, and the impact that postsecondary education programs make on students with ID is mostly unknown. Students' daily experiences, especially social ones, have not been documented. Attributed abilities and methodological barriers reduce opportunities for

students to describe their social experiences. The current study directly addresses these challenges. In the 2012-2013 academic year, Students photographed and described their experiences participating in higher education. Typically developing peers, known as “Supports,” also contributed opinions and observations of Students’ social experiences in the campus community. Through the process, Students co-created knowledge, meaning, and identity through their shared relationship with their campus community. Supports contributed to and sometimes complicated Students’ creations. The PSE program and campus community were evaluated and recommendations were formed to further increase Students’ self-determination and inclusion. Processes and analyses used to create recommendations and address research questions are further explained in Chapter 3.

## CHAPTER 3: METHODS

With limited understanding of how Students (i.e., college students with ID) perceived social inclusion on college campuses and with insufficient tools for measuring the construct, inductive research was required. Descriptions of social experiences and Student generated definitions of social inclusion were sought to develop meaning for the concepts like ‘full inclusion’ which some PSE programs claimed existed within their respective campus communities. The section below provides an outline of sampling groups, procedures, and analyses used to develop an increased understanding of Students’ social lives and determine whether students were socially included in their campus community

### **Research design**

#### *Mixed Methods, Triangulation, Convergence Model*

Two groups of college students shared social inclusion insights. Students made one group and their typically developing peers, also students at the university, comprised the other. Because they were endogenous to the campus community, peer assistants were “natural Supports.” All natural Supports were listed in the PSE program’s volunteer database. Some Supports had worked with Students for three years while others had less than a semester of familiarity. Some received college credit for their involvement with the program, others were paid, and another subset was volunteers, but all were given equal opportunity to contribute their opinions about Students’ social support and loneliness.

The questionnaire was cross-sectional, an encapsulated set of opinions from the fall semester of 2012. The Support questionnaire was collected first, and Supports’ perspectives

were included again through three focus groups in the last phase of data collection. Only paid Supports participated in focus groups which were composed of different sets of Supports over a three day period in April, 2013.

Between the questionnaire and the focus groups, a photovoice project ran for eight weeks. Students participated in four weeks of data collection preceded by four weeks of research training. As participant-researchers Students collected and interpreted data to make meaning from their social experiences in the campus community.

The three participant groups each shared narratives through different mediums. Some paid Supports told their stories through survey and focus groups. Regardless of group or method, data were viewed as complementary, but unequal because emphasis was placed on Student interviews. The type of triangulation design which best modeled the data collection processes was the convergence model (Creswell & Plano Clark, 2006). In this model (Figure 3.1), data describing the same phenomena, social inclusion, were collected separately, analyzed, and results are compared. Both forms of qualitative data merged into a common analysis-- compared together before evaluated against questionnaire results.



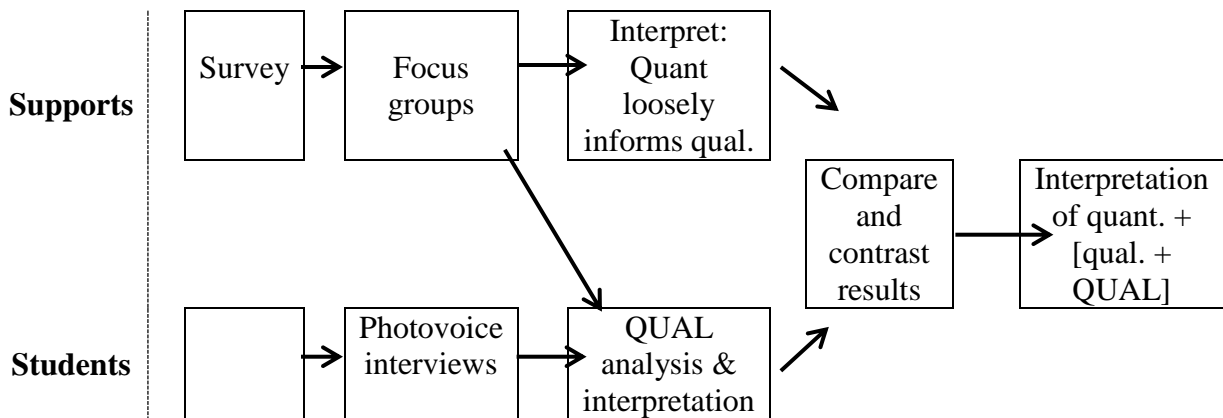


FIGURE 3.1. *Triangulation Design for Assessing Social Inclusion*

Student data, flanked by Support data, was the center of the study and emphasized in importance (as represented with ‘QUAL’ in Figure 3.1); all other views were used only in comparison to student perspectives. Preference was given to Students’ data because their status as knowers, even of their own experiences, had been previously marginalized. The study sought to move Student perspectives from the periphery and make them central to the study. From this value-driven, epistemological stance, Students were also in the best position to answer research questions. Students were seen as having insights about their social experiences that could not be directly accessed by others without intellectual disability (O’Donovan, 2010).

Despite the centrality of Student data, the design was still conceptualized as a variant of a mixed-method triangulation model where data were collected separately but converged for an overall interpretation. However, though data were collected separately they were not viewed as mutually exclusive. All participants interacted regularly and together they created

meaning. When Students described their social experiences, Supports were always part of the narrative. In the grounded theory process the groups and their data were interconnected. Students were primary contributors in the grounded theory process, but through theoretical sampling, Supports were guided by the investigator to respond to Student themes on social inclusion. The connection between Student and paid Support data is denoted with an arrow leading from “photovoice interviews” to “focus groups” in Figure 3.1. Furthermore, in the last stage of the model where interpretations were combined, the two qualitative methods, Student interviews and paid Support focus groups, are bracketed to signify the order in which mixed interpretation occurred. Qualitative data were first mixed and then later compared to Student survey results.

### **Participant Selection**

#### *Students with intellectual disability*

This study sought the participation of seven students ( $N = 7$ ) that attend classes and work, and lived in residence halls at a medium-sized, rural, public university. Each student was also identified as having intellectual disability. The targeted sample size was approximately the same as previous participatory research studies including people with ID (Paiewonsky, 2011; Moya, 2009; Jurkowski, 2007; Jurkowski, 2009). All Students had to be eligible for IDEA services during their kindergarten through high school education, and no Students received a high school standard diploma or GED. To complete college certificate requirements, the set of Students worked in campus internships for a minimum of ten hours a week and they audited between five and ten hours of college classes. All Students, like their undergraduate peers, ate in the dining facilities, exercised in the recreation center, attended

sporting events, and fulfilled individual interests daily. Unlike many of their undergraduate peers, Students were supported by peers at work, in class, and during homework. Depending on Student support needs, assistance was also provided when traveling on campus, completing morning and night routines, and dining. Three of the prospective participants were women between the ages of 20 and 24 years. The other four prospective participants were men between the ages of 19 and 22.

### *Supports*

The PSE program defines college-age ‘natural supports’ (Supports) as paid and unpaid university students of approximately the same age as Students who intervene as necessary to facilitate participation in dorm-life, course work, and social & recreational activities. Examples of Supports’ tasks, partitioned by role, are further described in Table 2. During any semester approximately 200 college students provide natural support for Students. The Support/Student ratio was greater than 20 Supports for each Student, though no specific Supports provided aide for only one student. Supports were recruited by the PSE program through service-learning and other required practical experiences for education and psychology classes. They were also recruited at job fairs and through a variety of campus advertisements. Typically developing college students were required to apply for Support positions, whether paid or volunteer. They were trained in either a face-to-face environment or online, and a support guidebook was available online to maintain necessary knowledge for providing support. Training included required approaches to take in the event of emergencies, how to treat students respectfully, and strategies for providing assistance to adults with ID. Supports also were trained to use the interface of internet-based scheduling

software, *When to Work*®. Through *When to Work* the PSE program scheduled Supports to assist students as needed from 1-15 hours a week. Some Supports, before transitioning to more generalized positions, begin as in-class academic Supports, facilitating participation in college classes and implementing strategies to make course content more accessible.

Supports were affiliated with a variety of academic programs ranging from nursing and management to education and recreational therapy. All Supports, unlike the Students, entered college under typical admission requirements. Most Supports ranged in age from 18 to 22 years with a few non-traditional students also providing support. The majority of Supports lived on campus and were seeking undergraduate degrees, though three were graduate students. Most Supports were women. This was consistent with studies suggesting that women have more favorable attitudes towards people with disabilities (Forlin, Fogarty & Carroll, 1999; Rice, 2009; Vignes, Godeau, Sentenac, Coley, Navarro, Jean, Arnaud, 2009).

Table 3.1

*Natural Support Roles and Supportive Actions*

<b>Role/ Support Type</b>	<b>Example Actions</b>
Academic support	<ul style="list-style-type: none"> <li>•Attending and supporting SWID in classes</li> <li>•Support/tutoring with projects and homework</li> </ul>
Social support	<ul style="list-style-type: none"> <li>•Attending sporting events</li> <li>•Campus social events (e.g., religious groups, cheerleading, swimming, clubs, movies, plays, ballgames)</li> </ul>
Vocational support	<ul style="list-style-type: none"> <li>•Serving as a job coach</li> </ul>
Personal Development support	<ul style="list-style-type: none"> <li>•Suitemate: morning and night routines</li> <li>•Personal care goals (i.e., health &amp; hygiene)</li> <li>•Attendance and input at person centered planning meetings</li> <li>•Help collecting data on IPCP goals</li> </ul>

*Paid Supports*

Twenty-five of the PSE’s Supports, in the 2012-2013 academic year, were paid for the services they provided Students. They were more experienced in serving as supports and compared to volunteers they possessed greater rapport with Students. Paid supports were often former volunteers who were assessed by the PSE program coordinator as dependable. They were also viewed as more knowledgeable of Students’ individual differences and more skilled at implementing strategies to best help Students meet college’s demands. More responsibility was required of paid supports, and compared with their unpaid peers they provided two or three-times as many hours of direct or indirect support. All paid Supports

evaluated and discussed their performance with the program coordinator at the end of each academic semester. Criteria for evaluation were dependability, initiative, decision making, professionalism, communication, and problem solving.

### *Purposive Sampling*

Sampling for all groups was purposive. Each population, Students, Supports, and paid Supports was known at the time of sampling. The investigator met weekly with Students for non-research purposes. In face-to-face discussions, Students were presented with the option to participate in the study. The study was explained with easy-read text. For Students who were not their own guardians, families were sent emails that explained the study. All Students were given study information, including benefits and risks, and they were given one week to decide if they wanted to participate. Six of seven Students agreed to participate in the study.

At the time of administration, 182 active Supports appeared in the PSE program's scheduling software. All Supports were emailed a brief study description and a link to the survey, and 74 (40%) responded. The sampling was purposeful, sending survey links only to Supports who appeared on Students' schedules between October and November of 2012. All emailed Supports met two criteria—they were enrolled in classes at the same university as the Students and they had previously, in some capacity, helped students meet environmental demands of the college campus. Two additional reminder emails were also sent at four-day intervals. Sampling was not random and results can neither be generalized to Supports affiliated with other PSE programs nor to all college peers who aided Students in the 2012-

2013 academic year. All Supports voluntarily responded to the survey and self-selection bias, among others, was a viable threat to validity.

Similar to the total group of Supports, aid Supports were recruited first through an email that was sent to all twenty-five Supports paid for their duties in the spring of 2012. Recruitment described the purpose of the study and why the subgroup of Supports was deliberately recruited. Through email, phone calls, or face-to-face interaction, Supports confirmed their interest in participating in hour-long focus groups. One week was given to confirm participation, and by the end of that week 19 aid Supports expressed interest. Next, five proposed focus groups and days, times, and locations were sent to all who agreed to participate. Based on the proposed times, 15 students were able to participate in three focus groups. The first focus group had three aid Supports and the next two focus groups were comprised of six each. Nobody participated in more than one focus group, and three men, one in each focus group, participated in the study.

### *Protection of Participants*

Photovoice projects and research with people with intellectual disabilities create challenging territories for IRB boards; collaborative projects with people with disabilities require considerable precaution. Individuals with intellectual or developmental disabilities are considered a vulnerable population and extra precautions must be taken to assure researchers do not take advantage of participants. Cognitive impairments can compromise decision making and increase the likelihood of participants assenting to perceived authority figures. People with ID may struggle weighing risks and benefits.

In some cases Students, though all over 18 years, were not their legal guardians. For individuals who are not their own legal guardians, this study sought permission, via email, from guardians. All Students, whether or not they serve as their own guardian, met with the investigator on a weekly basis. In one weekly meeting the researcher reviewed a participants' rights document that was written for lower literacy readers and included pictures to explain participants' rights in a participatory research process. During the same session an IRB consent form (see Appendix A), also placed in a low-literacy format with pictures, was reviewed. While much of the information in the consent forms was redundant to the rights document, the former served as a measure to increase the likelihood of rights comprehension while the latter was more specific to the study and provided opportunity for candid discussions about purposes and responsibilities associated with the study. After reviewing the documents the investigator asked each Student if they wanted to participate in the photovoice project and they were given a week to consider their participation.

Protections for Supports' participation in the online questionnaire and focus group were typical for the formats and were not modified in ways similar to Student consent processes. The first page of the internet questionnaire was an IRB consent form. Supports who wished to participate in the study had to consent before answering questions. The survey did not collect any identifying information such as names, email addresses, or internet protocol (IP) addresses. All Supports who participated in the survey were eligible for one of two available \$50 Visa<sup>®</sup> gift cards.

All paid Supports who participated in the focus group were read a consent agreement and were also given printed versions to follow as desired. To confirm that they understood



the purposes, risks, and benefits of the study, participating Supports signed release forms. Regardless of the extent of contribution, each Support was paid \$10 in cash for their presence at the one-hour focus group.

All data were stored in separate protected files on the investigator's external hard-drive, which always remained in the investigator's possession. Raw survey data were downloaded in Microsoft Excel format and later transferred to IBM SPSS (Statistical Package for the Social Sciences). Interviews and focus groups were all recorded with a digital, audio recording device. Audio files were removed from the recording device and placed on the investigator's external hard-drive. Because Student and Support names were mentioned in interviews and focus groups, the investigator inserted pseudonyms during transcription. Like other forms of data, Student photographs were stored on the investigator's external hard-drive. Only photographs that did not include human subjects or ones where subjects had signed photographic consent forms, were used in the study.

## **Procedures**

### *Photovoice & Photovoice Interviews*

The study sought Students' interpretations of their social experiences within the campus community. It was an inductive and descriptive research process implemented to expand awareness and understanding about ways Students experienced social inclusion. Photovoice, a combination of photography and interview, facilitates traditionally marginalized participants as they use cameras to capture their lived experiences (Wang & Burris, 1997; Wang, 1999). At its essence, photovoice aims to understand lived experiences.

Photovoice invites participants into the research process by training them to collect data and photographs, and to communicate their lived experiences.

The photovoice design (see figure 3.2) began with four weeks of training and concluded with four consecutive weeks of students analyzing, through interviews, the data they collected. Student interviews were approximately one hour each, but varied depending on depth of Student descriptions and the number of pictures discussed, which typically ranged from three to six photographs.

Student photographs functioned as elicitation devices to help Students communicate their social experiences. Students were asked to photograph social experiences which included descriptions of social activities and their relationships with people in photographs, but also time spent alone. Images and narratives, Students were reminded, would be used to educate and influence decisions, particularly by the PSE program. Despite questions and feedback from the investigator, Students remained in complete control of their data's visual and verbal rhetoric.

The investigator guided interviews using the SHOWeD heuristic (described below). Answers, brief or detailed, were probed for additional information through variations of initially posed SHOWeD questions (also included below). When acronyms were used, unfamiliar relationships described or ambiguous details given, students were probed for additional explanatory detail. Interview transcripts were not completed between interviews. Instead, the researcher created brief memos during the interviews and when listening to audio recordings. Initial interpretations consisted only of Students' repeated ideas which were

discussed between Students and the investigator. Interpreted themes were confirmed by Students who never objected to theme interpretation. Opportunity for contributing additional detail was offered but seldom used. Major interview themes, such as the relationships between Students and Supports, played a role in shaping Support focus groups. Interviews iteratively related to photography. Through photographs students analyzed their social experiences and added meaning. New meanings or missing meaning partly contributed to photographs sought in subsequent weeks.

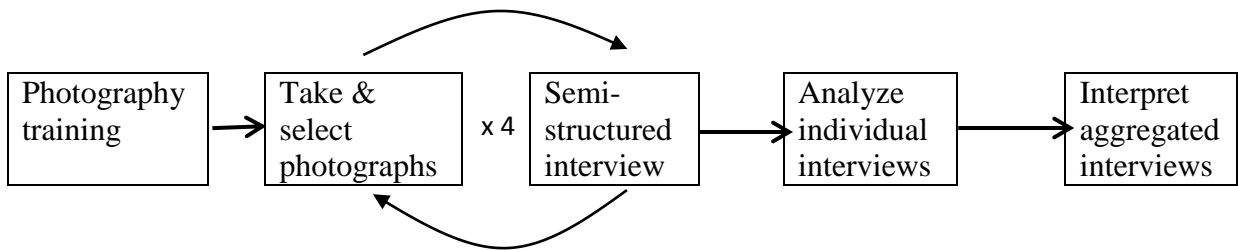


Figure 3.2 *Photovoice Design*

Research was viewed as a skill and ‘researcher’ as a role. Regardless of participant-researchers’ intellectual abilities, they were responsible for the safety and well-being of their photographs’ subjects. In one-on-one settings with the investigator, students completed training modules. The modules, guided by practices from the pilot project, are outlined in the Description of an Informal Pilot section.

With the exception of one student who participated in a high school research project, none of the students had previously been invited to co-evaluate their experiences, programs, or policies designed to serve their needs. Students were familiar with the words ‘research’ and ‘evaluation’ but they were unfamiliar with purposes, practices, and responsibilities associated with each. Research was described as a process of asking questions, collecting

information, and analyzing data with the goal of creating knowledge. Students were given examples of research questions and were asked to think of some strategies and methods they would employ to answer posed questions. Definitions were simplified to make research more accessible. The primary objective was to help participants understand their role in creating knowledge about social experiences for individuals with ID in a college setting.

Evaluation was discussed through the lens of program evaluation. Students were all familiar with one program: the postsecondary education program in which they participated. Programs, Students were told, put ideas into action with the hopes of making change. Lists that outlined the PSE program's goals were built by each Student. Students brainstormed with the researcher ways to measure whether goals were being attained. Program evaluation was described as research processes for understanding whether programs were making intended changes for intended stakeholders. Photovoice was described in the context of data collection for the purposes of research and evaluation. Each student agreed to take pictures and tell detailed stories about their daily college experiences to help the program and the university better serve all students.

### *The SHOWeD process*

In addition to being researchers, Students were storytellers. The investigator explained that all stories were valuable and valid, and that all people are experts in their experiences and should have the opportunity to tell their story. Students were taught that personal narratives were resources that should be equally distributed across all people

because when people did not control the production and distribution of their stories, they were more likely to be mischaracterized or stereotyped.

Details, however, were essential for all stories. Students were shown a picture and told two stories. The first story was only one sentence, lacking the sufficient detail to answer audience questions. Students were given the opportunity to ask questions about what they still wanted to know, like Who were the people in the picture? Why were they where they were?, What were they looking at? What was their relationship with one another? The second story answered all those questions, thereby modeling ways to provide more detail when telling a personal story.

Students were also given a heuristic to help them tell their stories. Storytelling can be challenging but with a series of guided questions, Students were provided an accommodation to help them share necessary narrative detail. The questions were based on those developed by Wang (1999) that form the SHOWeD acronym.

What do you **S**ee here?  
What is really **H**appening here?  
How does this relate to **O**ur lives  
**W**hy does this situation, concern, or strength exist?  
What can we **D**o about it? (Wang, 1999, p. 188)

However, the questions were modified for the Students and more closely resembled those used by Power, Freedman, and Pitner (2011) who trained adolescents to participate in a photovoice research project. Their version of SHOWeD was:

What do you **See** happening here? (Describe what the eye sees)  
What is actually **H**appening here? (What is the unseen story behind the picture? What does the heart see?)  
What does this photo tell us about life in your **cO**mmunity?  
Why are things this **W**ay? (Why does this situation, concern or strength exist?)  
How could this photo **E**ducate people?  
What can we **D**o about it? (How does this photo provide opportunities for us to improve life in your community?)

The final version of the SHOWeD heuristic that appeared in the training expanded on the intent of each question. The goal was to use the principles of Universal Design for Instruction (UDI; Scott, McGuire, & Foley, 2003) to reduce complexity and abstraction and increase flexibility by asking variants the same questions. The SHOWeD questions used in photo voice interviews were as follows:

Describe what you **See** happening in your picture? Just describe what your eyes see.

Is there anything **H**appening here that the eye can't see? How did you feel when you took this picture? How did you feel looking at the picture? What about the event or place in the picture makes you feel this way?

What does the photograph tell us about life in the college campus **cO**mmunity? What does it say about how you fit in the community?

Why are things the **W**ay they are in this picture? (As an alternative, instead of using 'things' insert students' description of events, places, or contexts.)

How could this picture **E**ducate people? What can other people learn about you by looking at this picture? What can they learn about your college experiences? What would you like others to learn from this picture?

What can we **D**o about it? If you like the situation, how can we make sure you have access to more situations like this one? If you don't like the situation, how can we change it?

The investigator used personal photographs to model storytelling by using the SHOWeD questions. Students then had an opportunity to practice the process by using a picture on their

Facebook account or on their phones. After each series of questions, the researcher provided feedback to help students add detail or clarity to their experiences.

Beyond training in communication and the narrative process, technical training was provided for the production of rhetorical photographs. Training included techniques for holding cameras that mitigated shaking and the consequential lack of clarity in photographs. Participants also learned about lighting, including instructions for when to use the flash, how to position subjects within a frame, how to alter angles to avoid distracting background structures, how to zoom in and out, and how to make sure appendages did not obscure the camera's lens. Technical skills were mastered differently by each Student depending on individual strengths. When Students displayed technical mastery through informal skill assessments they 'graduated' to ethics training.

Ethics training in the photovoice process was essential for participant safety and for the safety of photography subjects. It also helped Students understand under which circumstances pictures can be embarrassing for subjects. Participants were trained in asking for permission to take pictures and they received training in how to obtain consent form signatures. By following these processes Students better understood how to respect the privacy and desires of their subjects while increasing the likelihood of their own safety.

Students were trained to understand which individuals who appeared in photographs were required to provide consent. This process helped participants differentiate between distal or obscured background figures and pictures' primary subjects. Differentiating between 'subjects' and 'objects' was a necessary skill to assure individuals on both sides of the camera remained safe. Student researchers were taught, through definition and example,

when a photograph meets specific criteria, it has a 'subject'. Subjects were described as the overt 'stars' of photographs. When the primary purpose of the photograph was to capture a person or people either posing or doing some action then a 'subject' was likely present in the picture. Subjects were also described as those who follow any photographer instructions, such as 'smile', 'move closer together', or 'let's turn a different direction so the sun is not at your back.' The primary criterion met by all subjects was their facial or body features could be clearly identified in photographs. The researcher also explained that multiple subjects could inhabit one photograph. For the purposes of research, subjects in any picture used as data were required to sign a photo release form granting permission to use the subjects' image or likeness for the purposes of research.

The only time a subject did not have to sign a photo release form was if the Students were the subjects of their photographs. A directorial role was required of Student researchers who wanted to be the subject of their photographs. In these cases the Student-researcher needed to recruit the help of others to operate the camera and capture a desired composition. Students practiced different ways to ask, "Can you take my picture?" to assure they would be polite enough during the request, but also to be confident in their ability to guide the recruited photographer to capture adequate detail in the shot.

'Non-subjects' or 'objects' were also not required to complete photo-release forms for the ethical use of a person's image. Non-subjects were considered all individuals who were peripheral to the photograph's purpose. Non-subjects could not be individually identified based on information present in a photograph. Often appearing in photograph's



mid-ground or background, non-subjects were not intentionally included in compositions and further information about them could not be provided during subsequent oral descriptions of photographs.

Objects, unlike subjects and non-subjects, were often inanimate or non-human. Buildings, landscapes, and animals could all function as a viable focal point of a photograph. However, it was explained that permission could not be granted from objects. Objects were attributed meaning to the extent they related to the photographers' narratives. Some environments, or objects located there within, are capable of evoking strong emotions in other people. Students were told to contact the principle investigator if they were not confident that environments or objects were safe or permissible to shoot.

After four weeks of photography and ethics training, Students took pictures in weekly intervals for four consecutive weeks. Each week students brought their photographs to research sessions. Students used their phones, i-Pads, and digital cameras to capture photographs. In some cases Students had already uploaded photographs to Facebook. During research meetings, Students were permitted to log-in to Facebook and share recently uploaded photographs. While the SHOWeD process for describing pictures provided initial structure, Students were permitted, at their discretion, to stray from the heuristic to describe their photographs, but the researcher always returned interviews to the basic structured outlined by SHOWeD.

### *Internet survey: Supports*

Modified surveys (see *Instruments*) were made accessible online through the SurveyMonkey platform in the first week of October, 2012. SurveyMonkey provides adaptable templates that can be shaped according to question types and response options. Supports were emailed hyperlinks that connected them to questionnaires. For three weeks the questionnaire remained open. In addition to the initial email that included the study description, two reminder emails were sent. Through the questionnaire Supports shared perceptions of Students' social experiences. The cross-sectional questionnaire was administered prior to Student photovoice interviews or paid Support focus groups.

A consent form served as the questionnaire's initial page; the remainder of the questionnaire was broken into four sections beginning with demographic items and one page for each survey. Within survey pages items were randomized, but page order remained constant. A link to the survey was sent to all Supports with contact information listed on the PSE program's scheduling software. The questionnaire was made inaccessible after the last week in October, 2012. Data were downloaded in Microsoft Excel form then pasted into SPSS, where reverse coded items were recoded, and subscale and scale scores were constructed through item means.

### *Focus Group: Paid Supports*

Three one-hour focus groups, moderated by the investigator, were held within one week in mid-April, 2013. The first focus group was comprised of three paid Supports and the next two focus groups had six paid Supports. One male Support was in each group. Each

focus group began with an explanation of ground rules and an orally presented consent form. All participating individuals signed forms to consent and were paid ten dollars in cash.

All Supports began by explaining their perceived PSE program roles and duties. The focus group questions were ‘open’ and while protocol created a format and planned discussion questions, responses were probed by the moderator. Further, Supports commonly responded to each other’s experiences, explaining how experiences were similar or different from their own. Discussion between Supports was encouraged. Though all focus groups began with the same set of questions, the moderator would address questions in varying order across focus groups where natural segues allowed. In the last minutes of each focus group, Supports were given the opportunity to submit final statements to summarize thoughts or readdress questions.

### *Instruments*

With the exception of demographics, Students were the referent for all questionnaire items. Social support and loneliness surveys were administered to assess Supports’ perceptions of Students’ social experiences in the college environment. Two social support surveys served as proximal measures for the quality of Students’ social networks. Items from the Modified Multidimensional Scale of Perceived Social Support (MMSPSS; Zimet, Dahlem, Zimet & Farley, 1988) were broken into three factors that related to the sources of social support whether family, significant other, or friend. This study only examined the ‘friends’ factor that captured whether Supports believed Students had friends on campus and whether those friends provided emotional and instrumental support. Through a five-point

Likert scale, Supports reported their extent of agreement (1-strongly disagree; 5-strongly agree) with statements about support from friends.

The MOS Social Support Survey (Sherbourne & Stewart, 1991) was used to complement the MMSPSS. The MOS measured subjective frequency of positive social interactions and emotional support. The former assessed how often Students engaged supportive friendship activities while the latter addressed how frequently Students' emotional needs were met by friends through a five-point Likert scale ranging from 1- rarely to 5-always. The total of three social support subscales served as vehicles for assessing the perceived quality of Students' friendships.

To assess a divergent measure of social inclusion, the Modified UCLA loneliness scale-version 3 (Russel, 1996) was administered. It recorded beliefs about how frequently Students were not included and supported by others in the college community. All items provided an opportunity for Supports to subjectively assess Student loneliness without specifically referring to loneliness. Frequency was subjective and measured through a five-point Likert scale (1-never to 5-always). Lower scores were indicative of less perceived Student isolation and more Student connectedness.

Social support and loneliness measures had been administered to respondents ranging in age and experiences and reliability has been reported under each occasion. However, all measures were created as self-assessment devices. In this study the measures were used as a method for Supports to share their opinions not on their support and loneliness, but that of Students. The modified uses invalidate previous reports of reliability, but the novel use

created a way for those familiar with Students' social experiences to answer research question two.

### *Informal Pilot Project*

A pilot study was used as an instrument to guiding practices used in the photovoice process. In the spring of 2012, the principle investigator field-tested participatory photography procedures with college students with ID. Students had an opportunity to share their college experiences with their college community, as well as state legislators, academics, transition specialists, and key decision makers. Most photographs captured inclusive spaces and relationships, and influenced the direction of the current study. While the project was neither intended to be a research project nor was it approved as one by the institutional review board, it did provide an opportunity to pilot photovoice procedures with Students. Primary lessons (see Table 3.2.) were used to inform 2013 photovoice training and interviews.

Table 3.2

*Lessons from a Photovoice Field-Test*

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**One-on-one training is better**

- Students move through training processes at different paces so group processes are exclusionary.
- In a group setting, students who showed less understanding of the project lost motivation.
- When multiple students describe photographs together, students with stronger communication capacities have a tendency to dominate conversations.

**Must implement motivational strategies**

- Students showed increased motivation when photography goals were structured as a scavenger hunt.
- For motivation and sustained interest in photography projects, students need a greater role in either generating themes or independently taking photographs of their choosing.

**Be flexible and ready to adapt procedures**

- The longer the time between taking a photograph and describing it, the less rich the description was.
  - Some students never move beyond concrete descriptions of photographs.
  - 1/3 of SWID lost their digital cameras and as a result were unable to bring photographs to multiple sessions.
- 

*Research Questions*

Social inclusion is viewed as a primary domain of quality of life (Schalock, 1997), but little is known about social experiences of college students with ID. Students and their families sought college opportunities that were congruent with their typically developing peers. The congruence between experiences are described by PSE programs claiming to be “inclusive” or “fully inclusive”, but such descriptors have neither definitions or evidence of the claims. Further, Students have not been given formal opportunities to assess their social

experiences and state whether inclusion is present in their college communities. Research questions were directly linked to the problems.

*Research Question 1:* How do Students describe and explain their social experiences that occur within the campus community?

*Research Question 2:* How are Students' social experiences described and explained by Supports?

*Research Question 3:* Do Students and Supports accounts provide sufficient evidence of Students' social inclusion?

Research questions 1 and 3 place Students as the primary surveyors of their college social experiences. Students described contexts, relationships, roles, benefits, and barriers to infuse meaning into claims devoid of meaning. Student input catalyzed change processes. They described phenomena which were previously unknown. They exposed needs for more social inclusion. Students also shared social contentment, and they described what elements contributed to positive perceptions of their social experiences.

Research question 2 proposes that when considering Student social experiences, natural supports have more familiarity than anyone else in Students' social networks. With family removed by physical distance and PSE program staff removed by roles and limited direct interaction, Supports, besides Students, were best positioned to comment on Student social experiences. Further, the extent of their knowledge allowed them to make claims about Student inclusion.

Administered methods were best suited to convey answers from populations best suited to answer the research questions. The photovoice process that valued Students as participant-researchers created an accessible pathway for Students to directly answer research

questions 1 and 3. Photovoice provided sufficient flexibility in photography and interviews for Students to make meaning of their experiences, but provided enough structure through guided interview questions to assist Students in describing their social experiences in concrete and abstract ways.

Paid Support focus groups created a safe environment for Supports to openly share the memories and observations, whether positive or pained, about Students' social experiences, and in the process, address research questions 2 and 3. The dialogue between familiar Supports who shared similar experiences garnered detailed images of Student inclusion and exclusion. Through focus group sessions, dialogue created environments for meaning to emerge and be amplified through group collaboration. Their perspective was neither confirmatory nor discordant with Student accounts, but focus group discussions did allow participants to express the complexity which surrounds social inclusion.

Surveys also addressed research question 2. The method allowed Supports to share opinions about Students' social lives without being personally identified. Some respondents feel safer responding with relative anonymity, and internet surveys provided the opportunity. Scales and subscales overtly measured loneliness and social support, but the items allowed Supports to share opinions about Students' friendships, social networks, and connectedness. No measure directly captured a validated social inclusion construct, but they reported on the quality of Students' social lives in the college community.

Because all the measures were used in an unorthodox manner, it was necessary to compare measures for basic convergent and discriminant validity. The investigator hypothesized that social support subscales, measuring quality and frequency of social



interaction with friends, should significantly and positively correlate (hypothesis 1). Similarly, the investigator hypothesized measures of supportive friendship (i.e., social support) regardless of modifications and formatting, should significantly and negatively correlate with loneliness (hypothesis 2).

#### Hypothesis 1

H<sub>0</sub>: R = 0, social support subscales are not related

H<sub>2</sub>: R > 0, social support subscales are related

#### Hypothesis 2

H<sub>0</sub>: R = 0, lonesomeness is not related to social support

H<sub>1</sub>: R > 0, lonesomeness is related to social support

Focus groups sought perspectives and narratives from only paid Supports. These Supports, it was assumed, had greater familiarity with Students and therefore, greater knowledge of their social experiences. With a greater time investment and more opportunity to witness Students' inclusion or exclusion, paid Supports, it was thought, would respond to social support and loneliness measures differently from their peers (hypothesis 3), but it was unclear whether increased knowledge would reinforce beliefs of Students' inclusion or exclusion. Examining response differences across support type provided indication as to whether paid Supports were more divergent or representative of their peers, an understanding which had implications for focus groups.

#### Hypothesis 3

H<sub>0</sub>:  $\mu_{\text{paid}} = \mu_{\text{unpaid}}$

H<sub>1</sub>:  $\mu_{\text{paid}} \neq \mu_{\text{unpaid}}$

Overall, methods and purposive samples were chosen for their abilities to best address the research questions: what were Students' social experiences? Were they included?

Hypothesizing outcomes and making predictions about Student social experiences and social inclusions do not best fit with stated problems or research questions. The intended outcome of the study was not to explain or predict, it was to build understanding of Students' social experiences and social inclusion in order to develop a theory so PSE programs, universities, and communities could enhance social inclusion for students with intellectual disability.

### **Data Analysis**

The investigator was a collaborator in forming meaning and creating understanding of Students' social experiences. Analyses chosen reflected the researcher's active role interpreting actions, setting and relationships to create meaning. The relationship with quantitative analyses was more indirect but was still influenced by the measures chosen and the modifications made to them. The investigator's role in qualitative analysis was more overt. By developing processes, asking questions, transcribing, and coding data, the investigator co-constructed experiences of social inclusion, and by moving these experiences through levels of abstraction, created a theory to directly address stated problems and research questions.

#### *Descriptive statistics*

Three surveys were administered to Supports through an internet survey. Responses, in addition to demographic data, assessed Student social support and loneliness. Three subscales across the social support measures were of particular interest due to their ability to

measure close social relationships. Sample size, means, and standard deviations of social support and loneliness provided Support interpretations of the quality of Students' social experiences in college.

The MOS Social Support Survey measured frequency of support located on a five-point response scale, ranging from never to always supported. Two subscales, Positive Social Support and Emotional Support, were of particular interest for gauging Students' social climate and included items such as "How often is each kinds of support available to [Students] when they need it?"; "Someone to get together with for relaxation" (positive social support); "Someone who they can count on to listen to them when they need to talk?" (emotional support). Means between "most of the time (4)" and "always (5)" were indicative of the belief that Students had emotionally close, supportive relationships on campus and that these relationships were accessed when desired. Descriptive data also reported the frequency of "most of the time" and "always" responses.

Close social relationships/friendships were of interest because such relationships comment on the quality of one's social experiences. The "Friends" subscale of the Multidimensional Scale of Perceived Social Support was particularly useful when determining the state of Students' social experiences within the campus environment. The "Friends" subscale included items such as "[Students] have friends at [the college] with whom they can share their joys and sorrows" and "[Students'] friends at [the college] really try to help them". Responses measured agreement to the social support statements of a five-point scale from "strongly disagree" to "strongly agree". Means ranging between 4 and 5 indicated 1) students had friends; 2) they could depend on those friends for support; 3)

students lived and learned in a supportive social environment, and frequencies of “agree” and “strongly” agree were reported.

Finally, descriptive statistics (means and standard deviations) were used to understand Support perceptions of Students’ loneliness using the UCLA Loneliness Scale, version 3. The scale was examined as a single loneliness factor that included reverse coded items such as “How often are [Students] part of a group of friends?” and non-reversed items like “How often do [Students] feel left out?” All items were measured for subjective frequency on a five-point scale ranging from “never” to “always”. For this measure lower scores indicated less loneliness, with scores between 1 and 2 indicating that students rarely, if ever, experienced loneliness, which is to say, they were socially included.

Descriptive data was useful for capturing general perceptions of Students in general. Surveys were structured to capture data only in aggregate form. While it is possible that Supports refer to observations of one or some of the Students when responding, no responses were directly connected to any one Student. The goal of examining descriptive data was to identify trends that would comment on Students’ perceived social experiences on a college campus. Seldom occurring loneliness coupled with frequent support from friends, for example, indicated that Students were viewed as having high quality social experiences and were not socially excluded.

#### *Bivariate correlation*

A correlation analysis was performed for scales and subscales that were particularly salient for understanding quality of Students’ social experiences. Theoretically the observed or perceived existence of friends and social support should not conceivably coexist with

observations or perceptions of loneliness. Bivariate correlations were used for discriminate validity to make sure scales performed as predicted. The analysis also confirmed trends that emerged through descriptive data. Strong perceptions of student engagement in socially supportive environments and the absence of loneliness would suggest that Students experienced positive social experiences.

*t-tests*

In an average week, paid Supports, compared to their unpaid peers, were more frequently scheduled to provide Student support. Most support shifts ranged from 45 to 90 minutes leading paid Supports to spend more total time with Students. Because paid Supports had more direct contact with Students they had more opportunities than other supports to directly and indirectly observe Students' social experiences. Because paid Supports presumably had an increased familiarity with Students, it was predicted that paid Supports' assessments of Students' social experiences would differ from the assessments of non-paid Supports. This hypothesis was tested using an independent sample *t*-test to compare paid and un-paid Supports' mean responses across three social support subscales and the UCLA loneliness scale. Common phenomena observed across Support types further rationalized using only paid Supports in theoretical sampling focus groups. Any response similarities across all Support subgroups indicated stability of observations and how paid Supports could share a common voice for the Support community on the specific college campus.

## **Qualitative**

### *Grounded Theory*

Photovoice interviews and Support focus groups were recorded and transcribed. Charmaz's (2006) constructivist grounded theory approach served as the primary guide for analyzing transcripts. Data were situated within specific contexts—students with ID from one PSE program in one university in the Southeastern United States in the Spring of 2013. Whether data were Student or Support explanations of social experiences, they were viewed as emerging from relational or group contexts. The presence of the researcher in all interviews and focus groups and that researcher's position as PSE program staff contributed to the co-construction of narrative. Similarly, the researcher held a significant role in transforming raw data into categories and eventually theory on social inclusion. The researcher was neither separate from the data nor entirely objective. Interpretation and analysis co-created knowledge by piecing together processes, connecting experiences from multiple participants, and moving implicit meaning of statements from the background to the fore. Researcher and participants were connected through all processes of grounded theory analysis, but all stages of analysis were always directly connected to data and all analytical stages (Chapter 4.) directly connected participants' statements with codes, category, and theory. An overview of each grounded theory stage is outlined below.

### **Analytical Steps**

#### *Initial coding*

Twenty-three Student interviews were recorded and transcribed. Interviews were coded incident-by-incident. Sometimes 'incidents' occurred multiple times in a single

statement while other times statements were comprised of multiple sentences. Most of the time incidents were located within each line of text. To keep data closely linked to student experiences, codes were kept active and often used Students' phrasing. As recommended by Glaser (1978), gerunds were used to construct initial codes to keep data active rather than descriptive alone. After interviews, initial coding was a second phase of research/participant interaction, though this time data construction occurred through the researcher's interpretation of Student statements. For each 'incident,' a code was applied that attempted to categorize and summarize fragments of student narrative (Charmaz, 2006). Initial codes were constantly compared to another during label making but were not combined into more parsimonious codes until later stages of analysis, like focused coding.

#### *Focused coding*

Students repeated ideas about their social lives throughout the interview process. Focused coding identified interpretations and descriptions that were common across Students' interviews. Further, in focus coding interpretations, actions, and observations were compared and combined across Students to derive major themes. To best understand social and environmental conditions that were likely to produce accounts of positive social experiences, focused codes also looked for similarities across contextual elements including 1) activities and spaces; 2) conceptualizations of social inclusion; 3) facilitators of social inclusion; and 5) barriers to social inclusion. Similar approaches to understanding contexts in which social actions emerge were recommended by Glaser (1978) who created coding families such as "Causes, Contexts, Contingencies, Consequences, Covariances, and Conditions" (p.74, as cited in Charmaz, 2006). Focused codes offered a tentative outline of

emergent theoretical models that increase understanding of Students' social experiences. A tentative theory became more pronounced through axial coding.

### *Axial Coding*

Axial coding further combined common codes to identify elements essential for constructing a theory to explain social experiences of students with ID living and learning in a campus community. To progress towards theory, the level of abstraction advanced during axial coding. Categories no longer described specific social experiences of specific students, they only described collective experiences. Categories were also assigned formal definitions that were more universal and inclusive of multiple social experiences. Each category's uniqueness was presumed to be pronounced enough to assure that it could not be logically combined or subsumed by another category. Categories were not returned to Students. Three Support focus groups were approached to share their observations about Student social experiences and complicated codes formulated from Student interviews.

### *Theoretical sampling*

By conceptualizing the ways the categories synced together to account for social experiences, the likelihood of social inclusion theory begin to emerge. Paid Supports provided a minimum of 250 hours (25 paid Supports were required to provide a minimum of 10 hours of support per week) of assistance with Students each week. These Supports also had known Students from one or more previous academic semesters. Therefore, given Supports' familiarity with Students' campus experiences, they were invited to explain aspects of Student social experiences that had not been previously described in interviews. Conversely, theoretical coding provided the opportunity for Supports to confirm and add



detail to Student categories which were developing the tentative theory of social inclusion. Supports were invited to elaborate on Students narratives about social inclusion, and Support focus groups were transcribed and coded with processes that were identical to ones used for analyzing Student interviews except that codes were narrowed to examine Students' social experiences and relationships between Supports and Students. Refined, collapsed, and additional categories were included in creating a theory that accounted for Students' social experiences.

### *Theory development*

Constructivist grounded theory is produced from the theorist's interpretations of fundamental elements of the studied social lives (Charmaz, 2006). Relationships between categories were integrated into a larger, more succinct framework. Theory sought to understand social experiences, and the constructed theory was specific to students at a specific college and did not make assumptions of generalizations and applications across multiple student populations and college environments.

The grounded theory process was guided by meaning generated during data collection and analysis. Every analytical stage, initial coding, focused coding, axial coding, and theoretical sampling, further advanced a theory's production. Data were not assumed to be exact representations of real life and analyses were not exact renderings of social processes. Further, the theory was not capable of explaining all processes, relationships, actions, or networks that contribute to social experiences. The constructivist account was meant to better understand the ways a set of Students interpreted experiences of social inclusion and exclusion on a college campus. More so, however, the constructivist perspective promoted a

pragmatic theory to encourage PSE programs and Supports to question their roles and assert power in promoting or preventing social inclusion, self-determination, and quality of life for college students with ID.

### *Mixed-Method Comparisons*

The mixed-method design was a convergent style of triangulation. Consequently, it is most appropriate to take steps aligned with convergent data analysis (Creswell & Plano Clark, 2007). Analysis was performed approximately separately for the questionnaire, focus groups, and interviews. Analyses for qualitative methods were not mutually exclusive because analysis of Student data created a framework through which to examine paid Support focus group data. Nonetheless, grounded theory coding was performed separately in that Support data were not aggregated with Student data, even though data were aggregated separately across all Student interviews and across all Support focus groups. Next, the researcher merged datasets and compared results, creating tables to describe ways data converged and supported one another. Divergence and differences across data also were reported.

### *Summary*

The procedures and methods used in this study were structured to address research questions and to take necessary steps for making programmatic and institutional change. Students and Supports were encouraged to describe their social experiences and critically assess why experiences were as such. Participants' descriptions and interpretations were analyzed in ways that further interpreted meaning. The results of the analyses are presented in the next chapter.

## CHAPTER 4: RESULTS

### *Introduction*

The study was conducted in multiple phases between October, 2012 and April, 2013 and relied on a variety of data collection methods. Each phase and method was dedicated to accessing Students' social experiences in college. Students and paid Supports generated qualitative data through interviews and focus groups, respectively, and Supports, paid and unpaid, responded to internet-based surveys. Analyses and the results of analyses are shared in this chapter to answer the principal research questions: What are Students' social experiences on a college campus and is there reasonable evidence to suggest that Students are socially included in the college environment? To answer these questions, the chapter will first share Support opinions, provided through questionnaire responses to Students' loneliness and social support in the campus environment. Next, the chapter reports Students' direct observations about their social experiences. Five primary grounded theory steps and the results of those steps are described, 1) initial coding; 2) theoretical coding; 3) axial coding; 4) theoretical sampling and analyses; and 5) theory construction. Stage four of the grounded theory process is guided by data from paid Support focus groups. Lastly, the chapter will briefly explain the ways portrayals of Students' social experiences and social exclusion either converge or diverge across analyses. Results from this chapter will guide a subsequent discussion about the implication of the findings for Students, the postsecondary education (PSE) program, and the field.

## Quantitative Results

Initially, little was known about Students' social experiences. One known element, however, was that Students received support to address challenges in academic, vocational, and social activities. Typically developing peers provided support, and theoretically each had an opinion about Students' social experiences. The administration of an internet survey, with Students as referents, engaged Supports' opinions.

At the time of recruitment, 182 students actively participated as natural Supports. 74 Supports, a mix of paid and volunteer, started the internet questionnaire and 62 completed the entire questionnaire. Nonetheless, at the beginning of the study no documented information was available regarding Students' social lives, but questionnaires provided initial insights.

Of the 73 survey respondents that reported their sex, 96% were women which was expected because more than 9/10 PSE program Supports at the time were women. Supports' mean age was 21 years and they worked or volunteered with Students for an average of 4.83 (s = 4.19) hours per week. One third (33%) of respondents (n=24) were paid and the rest (67%) either volunteered or received service learning credit in return for their assistance. Nearly half (48%) of respondents were in their first semester of support, and rest had provided support for 2-6 academic semesters, some supporting three Student cohorts.

### *Descriptive results*

Descriptive data are used to report the findings from The MOS Social Support Survey, Multidimensional Scale of Perceived Social Support, and UCLA Loneliness Scale. As a reminder to the reader, these scales provide proximal assessments of the quality of

Students' social lives. Supports described Students' social lives to the degree possible within the scope of the questions asked.

The MOS was comprised of two subscales that measured how often positive social support and emotional support were available in the campus community when Students needed them. Five response options ranging from never (1) to always (5) were available; therefore, greater results equated to greater amounts of perceived support. Items were averaged to create composite scores for subscales. In most cases, subscale scores were not whole numbers. As a result, score ranges are presented (see Table 4.1). Generally, Supports reported that Students had positive social support and emotional support when needed (see Table 4.1). Students were viewed as having positive social interactions and emotional support subscales, 87% and 86% of the time respectively, and the mean for both subscales was approximately 4.5 on the 5 point scale.

Table 4.1

*MOS Social Support Survey Descriptive Results*

Subscale score range	<i>f</i>	%	Cum %	Mean (SD)
<i>MOS Positive Social Interaction</i>				4.49 (.50)
1-1.99				
2-2.99				
3-3.99	8	12.9	12.9	
4-5	54	87.1	100.0	
Total	62	100.0		
<i>MOS Emotional Support</i>				4.49 (.52)
1-1.99				
2-2.99				
3-3.99	9	14.5	14.5	
4-5	53	85.5	100.0	
Total	62	100.0		

Similarly, Supports reported that Students received strong social support from their campus friends. The friends support subscale included items which gauged whether Students had campus friends who were helpful, dependable, and good listeners and whether or not Students' life events were going well. Supports responded with the degree to which they agreed with statements about Students' social supports. Responses closer to 1 indicated that Supports perceived students to not be supported by friends, and conversely responses closer to 5 indicated that support from friends was provided. Table 4.2 shows Supports perceived Students as socially supported by their campus friends, suggesting 1) students had friends and 2) those friends provided high quality social support. 94% of Support responses indicated

agreement or strong agreement with statements about the socio-emotional support Students receive from friends in the campus community.

Table 4.2

*MSPSS 'Friends' Subscale Descriptive Results*

Subscale score range	<i>f</i>	%	Cum %	Mean (SD)
<i>MSPSS Friends</i>				4.54 (.61)
1-1.99	1	1.5	1.5	
2-2.99				
3-3.99	3	4.5	6.0	
4-5	64	94.0	100.0	
Total	68	100.0		

In addition to reports of Students' strong and available social support from peers in the campus community, Supports also reported that Students rarely experience loneliness (see Table 4.3). The scale measured frequency of experienced loneliness. Results closer to 1 meant Students less frequently experienced loneliness while results closer to 5 meant Students were experiencing more loneliness. 95% of Support responses reported that Students were never or rarely lonely. In sum, Supports' opinions indicated that Students were seldom lonely and received reliable social support from friends on campus. Total survey data showed no evidence of social rejection or exclusion.

Table 4.3

*UCLA Loneliness Scale Descriptive Results*

Subscale score range	<i>F</i>	%	Cum %	Mean (SD)
<i>UCLA Loneliness</i>				2.01 (.43)
1-1.99	28	45.2	45.2	
2-2.99	31	50.0	95.2	
3-3.99	3	4.8	100.0	
4-5				
Total	62	100.0		

**Inferential results**

*Correlational Analyses*

Theoretically, social support serves as a barrier to loneliness, exclusion, and isolation (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Lippold & Burns, 2009).

Confidants, friends, and emotional support should not co-occur with loneliness- the sense one has no friends or social support. Accordingly, Supports' loneliness opinions were hypothesized to significantly and negatively correlate with social support responses which were hypothesized to significantly and positively correlate with one another.

H<sub>0</sub>: R = 0, lonesomeness is not related to social support

H<sub>1</sub>: R > 0, lonesomeness is related to social support

H<sub>0</sub>: R = 0, social support subscales are not related

H<sub>2</sub>: R > 0, social support subscales are related

All scales or subscales were significantly correlated (see table 4.4). Social support from friends, emotional support, and positive social interaction each had strong, negative correlations with loneliness. Social support subscales within or across scales had significant,



positive correlations. Each of these relationships was hypothesized and both null hypotheses were rejected.

Table 4.4

*Bivariate Correlations Among Observations of Loneliness and Social Support*

Subscale	1	2	3	4
1. UCLA Loneliness	--	-.47**	-.48**	-.40**
2. MSPSS Friends		--	.40**	.31*
3. MOS Emotional Support			--	.75**
4. MOS Positive Social Interaction				--

Note: Correlations marked with (\*\*) were significant at  $p < .001$  and (\*) at  $p < .01$ ; one-tailed

*t-tests Analyses*

Paid Supports were expected to hold different opinions than their peers when regarding Students' social lives. The two groups were divided by differences in support experience, training, and time spent with Students. The PSE program recruited most paid Supports because as volunteers they had shown a dedication to Students that separated them from their peers. They asked for more shifts and often spent time with Students even when they were not scheduled to do so. While Supports came from all majors, Paid Supports, with few exceptions, were studying special education or communication sciences and disorders. Time with Students for paid Supports was often of personal and professional interest. Paid Supports needed a minimum of one semester's experience and all were required to provide support for more than 10 hours a week. Amount of time spent with Students was predicted to

create disparity between paid and unpaid Supports' opinions. More time spent with Students was thought to be associated with familiarity, closeness and rapport, and that knowledge, it was predicted, would influence paid Supports' perceptions about Students' social lives to differ from their unpaid peers. Therefore, it was hypothesized that paid and unpaid Supports would have different mean scores on the social support and loneliness measures.

$$H_0: \mu_{\text{paid}} = \mu_{\text{unpaid}}$$

$$H_1: \mu_{\text{paid}} \neq \mu_{\text{unpaid}}$$

Contrary to prediction, paid and unpaid Supports responded similarly across all reported measures. Regardless of experience, training, and responsibilities, both groups viewed Students as socially supported and rarely lonely (see table 4.5). As a consequence, the null hypothesis that stated the two groups would have equal responses could not be rejected. Though survey responses were similar across paid and nonpaid Supports, only paid Supports were invited to the subsequent focus group phase of the study. The rationale being that focus groups did not restrict the range of narrative or response options the ways that surveys did, and that paid Supports, again because of their time with Students, would be able to produce more detailed observations and narratives than their unpaid peers. Also, similarity of survey responses between paid and unpaid Supports was viewed optimistically because surveys showed that paid Supports, in focus groups, had the potential to share views representative of the larger Support community.

Table 4.5

*Independent Sample t-tests comparing paid and unpaid Supports*

	Paid Supports Mean (SD)	Unpaid Supports Mean (SD)	<i>t</i> ( <i>df</i> )	<i>r</i>
UCLA Loneliness	2.01 (.31)	2.00 (.49)	0.13 (60)	.02
MSPSS Friends	4.65 (.45)	4.49 (.67)	1.01 (66)	.12
MOS Emotional Support	4.40 (.49)	4.53 (.54)	0.85 (60)	.10
MOS Positive Social Interaction	4.43 (.50)	4.53 (.51)	-0.70 (60)	.09

Note:  $p > .05$  for all independent sample *t*-tests; all scales ranged 1-5

### Qualitative Results

In addition to the Support questionnaire, two more steps of data collection occurred in this study. The first was interviews where Students used data they collected in the form of photographs to lead discussions, and the second were focus groups with paid Supports. This section describes the results in that order. Data from 23 Student interviews and three focus groups were recorded, transcribed, and analyzed through grounded theory processes that merged data from both methods and samples. The theoretical sampling stage of grounded theory provided an initial framework for examining convergence and divergence of photovoice and Support focus group narratives describing Students' social inclusion.

## **Students**

In the 2012-2013 academic year, seven Students participated in the postsecondary education program for students with intellectual disability. Participatory action research roles and duties were presented to each Student, and all but one student accepted extra responsibilities associated with describing one's social existence. Table 4.6 reports basic demographic information for the six Students served as participant-researchers in the photovoice process.

The researcher held a staff position within the program which was imbedded within the university. Throughout the academic year, Students met with the researcher on a weekly basis for non-research purposes. When the study began, Students continued their routine by attending nine weekly hybrid meetings, at approximately 60 minutes each, that met the criteria of non-research and research meetings. The last three-quarters of each meeting were dedicated solely to Students' research on their social experiences. A review of the study as well as an informed consent presentation and discussion took the duration of the first meeting. Students were given a week to reflect on the study's benefits and risks, and at the second meeting they declared their participation decision. At subsequent meetings each Student had the opportunity to reaffirm their willingness to participate in the study. Consent or assent for Students who were not their own guardian marked the beginning of training. As previously described, Students participated in a series of photography and ethics trainings, followed by four weeks of data reporting and interviews.

Table 4.6

*Student Information*

Participant	Sex	Age/Ethnicity	Disability	Year in Program/High School Completion	College Activities
Kerri*	F	20/ Multiracial	Borderline ID (IQ= 75), 18p chromosome abnormality	Second-vocational track diploma	Dance, outdoor trips rafting, River Clean Up, religious organizations
Joy	F	20/Caucasian	ID (IQ= 53), Waardenburg syndrome, epilepsy	Second year-certificate of completion	Group exercise classes, campus arcade, outdoor trips, cooking, sporting events
Holly	F	23/Caucasian	Borderline ID (IQ = 73), Myotonic dystrophy, asthma	First year-certificate of completion	Concerts, sporting events, Equestrian club, sorority
Emanuel	M	21/Caucasian	ID (IQ = 49), Down syndrome	Second year - vocational track diploma	Cooking, ballgames, Special Olympics basketball
Kelvin	M	22/Caucasian	ID (IQ = 61), Autism	First year-vocational track diploma	Asian Students Association, fraternity, International Students Club
Zeke	M	22/Caucasian	ID (IQ = 55), Down syndrome	First year-vocational track diploma	Sporting events, concerts, public speaking, fraternity

Note: \*All names used in the study are pseudonyms.

Photographs served as an extension of commonly used communication styles. Some Students with lower literacy levels used pictures on their daily activity schedules to organize their days. Pictures were used as reminders in the workplace. A series of photographs and graphical representations built task analyses to guide Students through the steps needed to complete job tasks. Sometimes pictures became rows on cleaning checklists that were mounted on room walls as a reminder of recommended steps to keep a clean living environment. Like many of their same aged peers, photographs were used for self-documentation. Pictures of experiences and relationships were posted to social media sites such as Facebook, where students presented narratives of college life. Experiences decoding and documenting aspects of daily life created a degree of familiarity with using photographs to describe the social lives that unfolded within the campus community.

Through photography and spoken description, Students held a significant responsibility in producing and interpreting data. A week of data collection produced varying information yields. Sometimes students presented two or three photographs and other times they chose to describe upwards of ten photographs.

Each photograph, whether taken with phone, i-Pad, or digital camera, was used more as an elicitation device rather than raw data. Students' interpretations of their photographs became the primary data source for the study. The SHOWeD process created a familiar template through which photographs were decoded for personal significance. Students described physical pictures, but SHOWeD helped Students also describe social contexts including actors, settings, conditions under which social lives existed or were blocked, and

responses to personal social experiences. While most of the subsequent analyses are constructed from common social experiences, Student profiles provide a brief introduction to the individuals behind the study and their interpretations of social lives that played out within the campus community.

### *Holly*

Holly was 23 years old and a self-proclaimed “people person”. She said, “I like to hang around people—different people” and “I just have a natural thing to want to go over and meet new people but—it’s just my natural instinct.” A sense of *connection* to the campus community came up repeatedly in Holly’s conversations, and she rebuilt her identity around perceived connections. Viewing herself as a *contributor* she spoke of connection with a group of fraternity brothers who were raising money for Autism awareness. Identifying as a college student, she felt connected to her collegiate peers through the school’s mascot and colors. She felt connected to brave and adventurous characters in books, but mostly she spoke of being connected with women she most admired, Supports who were sisters in a particular sorority. “I actually made friends with some of them,” she stated. She described how she would hang out or eat lunch with the sisters, or even help them plan for ‘formals’. However, her greatest source of connection was also one which highlighted her liminal status. She pined one day that if she were in the sorority, “I’d probably have more people—more friends and be able to do more stuff on campus”. Holly’s sense of connection seemed to contrast with her descriptions of meeting others and being treated well, but never quite achieving full membership.

### *Joy*

Joy was one of the younger Students. During her second year in college she was 20 years old. She derived happiness from supports, friends, and family- three groups which she described with significant overlap. Supports accounted for the majority of her friendships and she described them in familial terms, “I’m part of the family here. The (college) family. We help each other a lot and [they] check on you when um-- and help if you need it.” By meeting her needs and making consistent appearances in her life, Joy developed an emotional closeness with Supports—they played a familiar role that she’d seen played previously by her family. Similarly, family members were friends and they were still preferred partners in social activities. Joy said, “This is my home family. We take—we sometimes, we stay at home but if sometimes we are bored we go somewhere or we do like family stuff...We go to the movies and shopping, and sometimes me and my mom we go ride bikes and stuff like that.” While the goal of the study was to capture campus social experiences, Joy often preferred to photograph and describe hanging out with her parents, brother, sister-in-law, “granny”, and aunt, and by participating in college life and gaining a college student identity she hoped to make her parents proud and prove to them “that I am ok living by myself and stuff like that.”

### *Emmanuel*

Emmanuel was a 21 year old Student on the verge of graduation from the college program. He built his identity and social networks through roles he obtained which were typically deemed valuable in society. He was a college student who was approaching the graduation milestone. At college, he had college friends, whom he frequently listed by name,



identifying them primarily as Supports and fellow Students. As a volunteer, he highlighted the way he *contributed* and gave back to the community. He described his work at a food bank and helping others with disabilities by saying, “Me help people in wheel chair to um (campus bus) to (residence hall). (Campus bus) and (residence hall) help lady wheel chair. Don’t know what name. Think of name uh wheel chair.” In such instances he was surrounded by his friends who were also supports. Emmanuel, however, constructed a primary identity around one action, “help people sick and hurt”, a phrase which he repeated frequently and reverently. He described taking E.M.T and first aid classes and volunteering with emergency responders on campus and in the community- “Volunteer help people sick and hurt and car wreck and female going to hospital. Take female to hospital. Take her to home.” He admired emergency medical responders and described them as his friends, but he took most pride in identifying himself as a paid employee with his home county’s medical responders. “This (home) county. Lot money for [work for] (home) county. I earn it. Help people.” Through valued roles and actions Emmanuel constructed a valued identity and a network of friend supports.

### *Kelvin*

Kelvin was a 22 year old who framed himself as socially self-reliant. He emphasized that required assistance from the program and Supports was limited as he built and maintained his social network. He attributed his social successes to individual skills and an inviting social environment. Of the former Kelvin said, “I can make friends through my own ways,” for example by joining multiple clubs, serving on committees, and utilizing technology to strengthen and maintain social connections. He realized his proactive social

stance was just part of his social success- the other factor was an open, inclusive campus environment which he described as “not discriminatory”, “very welcoming”, “open”, and “peaceful”. He said, “I fit into the campus community...the people on this campus are very friendly and nice and how everyone likes to hang out and kind of meet new people”. He described a reciprocal relationship with the community—he had a role in making it inclusive, not just benefiting from its inclusiveness. Through actions such as educating others about Autism and intellectual disability or celebrating diverse cultures and ethnicities, he actively contributed to an increasingly inclusive campus environment. Kelvin also appreciated the PSE program but quickly identified it as the primary barrier to his inclusion. He felt the program, though well meaning, limited his choice and freedom.

### *Kerri*

Kerri was a 20 year old Student in her second year of college. She emphasized the benefits of ‘alone time’ when she said, “I might just need an hour for alone time if I have leisure time I will just do whatever because I’ve been hanging with people all day.” She also described a small friendship network, primarily comprised of Supports, Students and family. She made it clear that friends had to meet and maintain specific expectations. Kerri even outlined stages of developing friendship. Based on investment, frequent social interaction, and the formation of trust, strangers could advance from acquaintances, to friends, and finally, to best friends. She felt acquaintances engaged her to fulfill scheduled obligations. She said acquaintances “are like a new volunteer or a new person that works along the way”; they “don’t really know you” and “you don’t know a lot about them.” Consequently, she maintained her distance and expected little of them. On the other hand, she described social

dependency on her best friend. Descriptions of her social life centered around one individual, who was simultaneously a best friend, scheduler, Support and suitemate. A singular focus on compatibility and friendship with one individual also became a primary barrier to Kerri's social inclusion within the broader community. For her, having one quality friendship with one Support was more important than developing multiple friendships with various individuals.

### *Zeke*

Zeke was a 22 year old, first-year college student who was eager to prove and project his competence. He sought and strengthened social relationships with others who recognized and honored his competence. Often he reported an affinity for his fraternity brothers: "You fit in very well with these guys. It's like you don't have a disability and that really makes yourself proud, make yourself to be like you're educated, make yourself to be like you're with anybody and that's how you get to know and how you get to be with friends, that's amazing." Zeke wanted to be recognized for being independent and able to balance requirements and recreation- like an adult. By completing tasks required for school and work he felt it possible to expand time available for participating in social leisure activities. He sought opportunities for public speaking because he felt valued, respected and in a position of power. In other words, he felt competent. Conversely, when he felt others denied him the opportunity to show his competence or if they removed his sense of competence, like how he felt during a group project, "being in a [college class] group basically if it is something that is like very important...I'm not supposed to really interrupt... they say what it is like and I can't say nothing. Like I will not know what they are talking about, basically," then he felt

devalued, misunderstood and eager to leave the situation. Zeke felt like he had many skills and had a lot to offer, and if others could not see that he did not want to share social activities with them.

*Research methodology applied to data analysis*

Constructivist grounded theory interprets data. The researcher, as primary interpreter, makes no claims at objectivity. Codes, categories and theory in this text are not an exact report of reality or a discovery of a reality heretofore unknown. Interpretations, bound to data, built meaning from participants' conversations and descriptions of actions.

Students and Supports undoubtedly spliced, rearranged, or remembered experiences in ways that were consistent with identities and values they hoped to project. Photographs were similarly projective, showing experiences which were not just salient to the social experiences of college students with ID, but to building the very identity of those Students. Students took photographs of segments of their lives that they wanted to remember and segments which would educate and influence memories of others. In focus groups, Supports made statements and recalled observations that served multiple purposes, two of which included sharing their perspectives of Students' lives and reinforcing place and status within the Support sub-community. Furthermore, the researcher's role as PSE program staff member influenced how realities were projected and interpreted. Researcher statements and IRB protocols overtly removed possibility of the program creating individual consequences for shared data. Stories and identities nevertheless were impacted by the interaction between

a program and research participants. In other words, data and subsequent analyses were contextually situated in interaction, place, and time.

Because the study sought to examine social experiences, data which described social actions and processes, or a lack thereof, were prioritized. Experiences interpreted as distally related to Students' social lives were whittled away in the grounded theory analyses. Categories which were not viewed as crucial to the process of making meaning were trimmed. Further description of coding and data analysis is provided in the results.

### **Initial coding**

The first stage of translating raw data, the participants' exact words, was initial coding. All coding was interactive. The researcher interpreted sets of transcribed text and began comparing interpretations within and across interviews, participants, and methods. In an attempt to stay close to data and avoid premature conceptual leaps, the researcher used gerunds where possible to summarize actions in participants' statements (Charmaz, 2006, p. 49). The goal was to summarize participants' experiences and create a more parsimonious dataset—one where several sentences used for describing a single incident were reduced to singular phrases: initial codes. Initial coding therefore focused on incidents. Sometimes incidents were captured in a single line of text, but often they were distillations of multiple sentences. The goal was not to replace participants' experiences but to interpret the essence of statements while assuring codes were always connected to raw data. To build upmost familiarity with data, the researcher conducted interviews, transcribed audio recordings, and coded data, bracketing observations and reactions to data at each intersection.

Initial coding from 23 combined Student interviews yielded 1,419 initial codes. Codes for each participant ranged from 149 to 298 and were largely determined by the amount of transcript produced. Students had approximately the same amount of time per interview, though they independently determined length and had the power to determine the termination point of each interview. Yet, some students spoke more about social experiences depending on ability, personality, number of photographs described, and investment in the participant-researcher role. Three initial coding examples are provided in table 4.7 below.

Table 4.7

*Initial Coding*

Student	Code #	Code	Excerpt
Emmanuel	Em24	<i>Helping</i> prospective students with physical limitations.	Me help people in wheel chair to um (campus bus) to (resident hall). (Campus bus) and (resident hall). Help lady. Wheel chair. Don't know what name. Think of name uh wheel chair. Spring break. No. Open house. That girl.
Kelvin	Kel155	Meeting friends through friends- <i>expanding social networks</i> via non-supports.	Carl, I met him last semester through my friend Lydia and he can do magic tricks. His nickname is 'Magic Carl' and we kind of talked about this other Carl who is an RA too and is called 'Average Carl'. (laughs).
	Kel156	Building familiarity with friends: sharing nicknames and in-group jokes; closeness and <i>membership</i> .	

The examples provided were included for a few reasons. First, structurally, the codes are representative of the majority of initial Student codes. Often, codes remained close to raw

data by transforming Student words into gerund phrases. Emmanuel's "Me help people" was transformed into the gerund "helping," while Kelvin's "I met him," became 'meeting'. Coding in this fashion prevented the researcher from extrapolating excessive meaning from any one segment of text. The gerund strategy, recommended by Glaser (1978), permitted the researcher to maintain a focus on actions which could be seen as a step in a process.

Often initial codes were not only reductions of Student text. Where possible, 'signposts' were also included. Signposts functioned as micro-memos that inserted explanation of Student descriptions. The first example from Emmanuel does not include a signpost, but data from Kelvin do. A few phenomena were highlighted from two sentences of text. Kelvin did not just mention that he met this friend Carl, he also described how he met Carl, which was through another friend Lydia. The process of meeting unfamiliar individuals through familiar individuals would go onto be an idea which could be compared with other Students' experiences. One element which was uncommon in the constant comparison was that Kelvin met another student through an individual who was not affiliated with the PSE program. This was relatively uncommon, so a micro-memo, "*expanding social networks via non-supports*" was inserted to describe the action in the gerund phrase "meeting friends through friends." Similarly, 'inside jokes' such as humorous nicknames derived from knowledge of individuals in a social circle was interpreted as an element of in-group status—it was coded "membership". In a different interview, Kelvin repeated the same pattern of communicating in group status by sharing a group derived Spoonerism of a member's name. Individuals situated within the group referred to the member by her Spoonerism nickname where those outside of the informal group referred to the member by her birth name. In initial

codes, gerund phrase retained closeness to the incident while the micro-memo interpreted the group actions.

Initial codes, like the ones in Table 4.7, created preliminary possibilities for data comparison. Primary ideas are situated within each code. Student ideas presented in a coded format, such as ‘helping’, ‘expanding social networks’, and ‘membership’, became signposts which could be compared to incidents. The constant comparative method (Glaser & Strauss, 1967) allowed incidents, described and interpreted as ‘helping’ for example, to be compared with other ways Emmanuel viewed himself as helping others in his community. Such incidents could also be compared with ‘helping’ codes from other Students or Supports. For example, in one of Joy’s interviews she also described a willingness to help others. Joy said, “I say “What do you need” and then they will tell me and then I would say, “Ok, I can take a couple of minutes to help you with something.” Students neither helped the same person nor did their helping occur within the same context, but the actions, words, and interpreted message was ‘helping.’ Subsets of similar initial codes held the potential to be elevated to focused codes and often did.

### **Focused Coding**

With the exception of one Student, all participated in four photovoice interviews. On four separate occasions, Students brought photographs regarding salient elements of their social lives. The first step in the focused coding process was to identify initial codes that were emerging as relevant across interviews. To meet this end, all single interview transcripts, codes included, were pasted together into a single document. Then, commonly



occurring initial codes that contributed to Students' explanation of social processes were compiled to search for similarities across Student interview sets. Commonly, the goal is to use major codes to guide analyses of large sets of data, but the researcher analyzed all transcripts with initial coding prior to moving to focus codes. Therefore, grounded theory stage became more about understanding which codes were significant and common across participants.

'Major' code status was determined by frequency of mention, significance of the code, or both. Significance was not necessarily correlated with frequency of mention but rather the inclusion and description of a message interpreted as a critical aspect of social experience narratives. Only one code, helping/contributing/reciprocity, emerged as a significant element of social experiences for all participants. Other codes that were significant for more than half of the Students were friendship (5/6), personal skills contributing to social participation (4/6), membership (4/6), social bridging/expanding social networks (3), exclusion/peripheral social status (3/6), and beneficial aloneness (3/6).

Through the focused coding process, categories became more broadly defined. Initial coding often included disparate information loosely based around what became common themes across interviews and Students. Varying manifestations of a particular phenomenon became united by their similarities rather than deconstructed by differences. To provide an example it is useful to return to an idea portrayed by Emmanuel in the initial coding table—helping (see Table 4.6).

Table 4.8

*Focused Code: Helping*

Student	Initial Code	Excerpt
Holly	<p>Helping raise money.</p> <p>Contributing financially through t-shirt purchase.</p> <p><i>HELPING OTHERS/ SHARED CONNECTION/INVESTMENT</i></p>	<p>I helped them raise money. I helped the Pi Kappa Phi raise money. They were selling t-shirts and I bought one of them. The t-shirts were for Autism Speaks.</p>
Joy	<p>Using phone to remember birthdays to wish others happy birthday- <i>reciprocity</i>- making others feel important/ valued.</p>	<p>I can like remember their birthday and send them a happy birthday message on Facebook. Happy. Like I didn't like forget about them.</p>
Kelvin	<p>Teaching others about autism and intellectual disability- <i>reciprocity/advocacy</i></p>	<p>Like the CSD students, when I talk with them sometimes I maybe help them to learn like when I talk about like the Temple Grandin book and teach them about that a little bit more about how they can learn from outside a book from a person with like autism or like the amazing memory that most people don't have. So I think I'm teaching them.</p>

Table 4.8 shows the varied manifestations of ‘helping.’ Helping for Holly in this particular situation was investment. Interest and money were invested to help support the fraternity’s fundraising activities while contributing to individuals with Autism (see image 4.1 a & b). Where social connections are built, investment is often found. By investing time,

money, energy, and interest in others, one helps others attain their needs and increases the likelihood of a return investment.



*Images 4.1 a & b.* Holly contributed to a fraternity that was fundraising for autism research. When describing photographs of the Greek letters and fundraising tent, she said she felt “connected” with the fraternity.

Joy also made an investment, but hers was of the emotional sort. By taking the necessary actions to make sure others had not been forgotten and to celebrate their birthdays, Joy made an effort to show friends that they were valued. She treated others the way she hoped to be treated, and in the process was investing her time and emotional energy in others. Relationships between friends or group members must have a degree of reciprocity to remain valuable for all parties, and by helping her friends feel valued she was playing a part in maintaining present and future social interaction.

Kelvin also described helping others, though his account did not include either financial or emotional contributions to provide help. Instead, Kelvin helped by educating others. Communication Science Disorder (CSD) students were learning more about

individuals with autism and Kelvin used his personal experiences to help the students better understand the topic. In the process of helping others he was also creating a more knowledgeable and comfortable community that was better prepared to accept individuals with autism.

Students ‘helped’ in very different ways, but each of them showed their contributions toward bettering their communities. Helping appeared in several forms across interviews and Students. Differences in details were subsumed by commonalities. How and where ‘helping’ was described was important but did not outweigh the shared code, helping, which showed the importance of social identity construction and maintaining value.

Differences in context fell to the background to make way for the emergence of common elements of Students’ social experiences. However, context remained important to the analysis and was pulled back to the forefront through a separate stage of focused coding. Targeted details from Students’ participatory social experiences were collected and compared to search for commonalities among contexts and processes under which the phenomena occurred.

After transcripts were reviewed twice each for initial codes and once more to interpret focused codes, they were reviewed once more to detail six contextual elements: 1) activities and spaces that became the stage on which social experiences were performed; 2) conceptualizations of inclusive social experiences; 3) individual, relational/community, and program conditions under which inclusive social experiences emerged; 4) barriers to inclusive social experiences; 5) consequences of inclusive social experiences.

### *Students' Social Inclusion*

Conceptualizing social inclusion requires a leap in abstraction from student explanations of social existence in a college community. However, through the focus coding process, convergent descriptions of 'social inclusion' emerged. Ways of being included and evidence of inclusion were described. Students felt included when they felt that they fit in and were treated as worthy (worth). If students described that their commonalities with those around them in a given environment exceeded their differences then they were describing an important element of fitting. Commonalities included shared identities, interests, and values. Joy, for instance, said "They will see I fit in the [college] community 'cause I'm a student". Another element of fit was acceptance. When students felt like they fit, they described relaxing or letting down their guard. More succinctly, students could behave casually or informally—they could be themselves, like Kelvin reported "we can kind of not just worry about being appropriate... and kind of just hang out casually." Fear of losing status because of one's abilities or competencies was reduced. To be clear, this type of fit is more consistent with 'fitting in' than the functional fitness described by the match between personal competencies and environmental challenges.

When students were assessed and treated as worthy, they also felt socially included. Inherently all Students, and all people for that matter, have value (i.e, dignity), but because social inclusion is a relational phenomenon, others' assessments and behaviors validate an individual's social worth. Students' assessments of social worth were cued by being invited to activities and being introduced by others. When others initiated or collaborated in the creation of future social plans students felt valued, as they did when it was clear that others

chose to participate in social engagements rather than participating out of obligation. Feeling invested in and being assessed as capable of reciprocating emotional and social investments were indicators that students were respected and deemed both important and useful. Holly summarized many of these observations when she said she was “able to be around people and not get nervous and getting included in some of the conversations and being asked if they can eat lunch with me even if they are not with me [as Supports] at the time.” When students felt respected and appreciated, their worth was recognized. Fit and worth are not the same, though presumably the more worth one is afforded, the easier it might be for one to fit in.

Students also described different ways which they understood themselves as included. Coexisting was the first. Descriptions of social inclusion which required lesser degrees of fit or acknowledgements of worth were described as coexisting. Coexistence included sharing life routines with peers in the college community. Patterns such as living on campus, attending classes, studying, navigating campus from one activity to the next, and dining on campus were shared among those coexisting. Students also shared campus facilities and spaces with their peers. Coexistence within the campus environment was used as evidence of inclusion and a shared ‘college student’ identity. Whether co-populating campus transit (see image 4.2) or events such as a football game, coexisting was one way Students described their social inclusion.



*Image 4.2.* Zeke shared life rhythms and resources with college peers. He said, the campus bus takes “us to our dorms and we also have a [campus bus] that also take us off campus also.”

Students described being known as more evidence of their social inclusion. Students felt that on campus they were recognized and acknowledged with a wave, greeting, and other methods. They were known by name and often knew others by their names. Kerri said, “I can go for a walk and say ‘Oh, there is someone that I know!’” Kelvin repeated the refrain, “You can just run into people randomly that you might not be expecting to see; we can kind of not just worry about being appropriate... and kind of just hang out casually.” Being known helped Students gain a sense of familiarity in the college environment and made it easier for them to feel part of something bigger.

Membership was the sense of being connected to something bigger than oneself—it felt like a part of something. Often social inclusion was described through membership. Perceived membership was accompanied with a shift in one’s identity and social location.

Distinctions between ‘me and them’ became the conclusion that ‘I am them.’ Membership could also be official as opposed to only perceptual. Being member of a group with social boundaries and limits on permeability made one’s in-group status official. By being part of a group that had finite membership and clear delineations of those who were in and out of the group, one was a member.

The final element of social inclusion which students described was friendships or close relationships. As Zeke said, “I’m involved with everything that is on campus and also I say that is because of well, it’s all about relationships and being friends.” Friends were often referenced as close relationships with other people in the campus community. Friends frequently interacted with Students which allowed for the production and maintenance of the relationship. The bonds formed from the interactions created an element of quality in the relationships. Friends were people who were reliable, dependable, emotionally close and trustworthy.

In sum, Students defined social inclusion as a relational experience with individuals or groups who recognized their worth and with whom they fit in. Conversely, when one’s fit or worth was questioned or rejected, Students’ social inclusion was diminished. Social inclusion/exclusion, as defined by Students’ college social experiences, was not exact and had multiple manifestations, but allowed for recognition of social inclusion when it was present, as well as a relative rankings of inclusion across contexts and Students.



### *Inclusive Activities and Spaces*

Most Student activities corresponded with the intended use of a space, and routine activities occurred within readily available spaces which could be accessed without the use of transportation. Routine activities that were shared with others included exercising in the campus recreation center, eating in dining halls, going to sporting events in stadiums and arenas, attending class in classrooms, and going to work at respective workplaces. Because they were routine aspects of most college students' schedules, focused codes for activities were mostly mundane. Many more student activities were unique to the individuals and became important parts of their stories and processes of inclusion. Some unique activities included attending out of town concerts with non-Supports; joining student clubs without formal support; volunteering off-campus with Supports; or going to a local casino with one's family.

Students cited two inclusive social experiences most often: hanging out and breaking bread. Hanging out, whether scheduled or unscheduled, was always informal creating the circumstances under which relationships develop. With a targeted action and specific goals always looming, little opportunity exists to get to know people. Breaking bread was described differently from the mundane task of eating. The goal was social not gustatory, therefore making 'breaking bread' a type of 'hanging out.' With meals scheduled for approximately one hour and eating taking less than half that time, social opportunities emerged.

Meals facilitated social experimentation. They provided a time and location to safely build familiarity with others, whether scheduled or encountered. Meals with friends became opportunities to brainstorm future plans, and one way to gauge another's interest was to invite them to a meal. If peers were not willing or consistently unavailable to share a meal then they would likely not become a dependable friend. Dinner was field for social experimentation where potential friendships dissipated or developed. With Kerri in particular, food spaces correlated with depth of friendship. Unfamiliar supports may be invited for coffee or a quick lunch. Dinner was prepared and cooked with Students and Supports who were friends, while one's most invested friends would transport students to share a meal at an off-campus restaurant. Of her suitemate and best friend Kerri said, "We always hang out, like on Sundays usually we'll have dinner together or we'll eat in my room and watch Amazing Race" and "You can get in your car and go off campus to eat anywhere...I'm happy I get to hang out with my friend." The more commitment in the relationship, the more time and energy was devoted to shared meals.

Kelvin on the other hand used meals as a way to invest in group membership. Shared meals became shared experiences that built group cohesion through a consistently developing shared history. Commitment to the informal group, the 'lunch group,' was shown by regular attendance at the lunch table. Kelvin described a photograph from his "lunch crew where we usually hang out on Mondays and Wednesdays. And in this picture I'm with one of the people from that group...we're not really a club. We kind of say we're the lunch group because we get lunch like on Mondays and Wednesdays." But for all students, meals were times to get to know others socially or to probe the depths of others' social investment. For

building and acting-out social relationships, hanging out and breaking bread were critical because they added flexibility to otherwise regimented schedules, and these situations provided opportunity for informal interaction.

### *Conditions Under which Social Participation Emerges*

Social activities in the campus environments required, at minimum, concerted efforts by two social actors. Students described various antecedents to participatory social activities, however minute. For the purposes of focused coding, three ‘parties’ identified as most responsible for the construction of social opportunity were Students, the campus environment, and the PSE program. Students often cited successful social interactions as the result of their making. Identities that the Students formed were based around acquired competencies and abilities to conduct their own affairs.

In situations where Students’ social participation occurred, Students attributed the social activities to their efforts. All Students described their skills and strategies to create social situations. They described the importance of initiating social plans by texting or calling others and soliciting shared activities. Zeke described his often employed method for creating opportunities for social leisure by saying, “you have to call them to see if they want to and if they want to do it... you will have to figure out how you are going to organize by riding, like how to go to it...I can call one of my friends and say...’Do you want to go somewhere?’ and they’ll be like, ‘Yeah. Sure. Why not?’” Another example of Students describing the ways which they coordinate shared activities was described by Kerri. “Sometimes on Fridays when I stay the weekend I’ll have like movie night and some people

will come and I invite them to watch stuff.” Similarly, Joy said, “through email and Facebook. I go on the talk thing and talk to them and see what they are up to and stuff like that. See if they want to hang out and all that stuff.” All students saw their social inclusion primarily as the individual’s responsibility. Conversely, instances of exclusion, though infrequently described, were often attributed to factors outside of one’s control, most often scheduling conflicts.

Students gave a variety of environmental antecedents to social interaction, most often the attitudes of other college students. The attitudinal environment, constructed by typically developing peers, was described as “welcoming”, “inclusive”, “inviting”, “peaceful”, “open”, “helpful”, and “nice”. By believing they were positively received by campus peers, Students felt comfortable meeting people and participating in social activities. Fear of adverse responses or descriptions of overt exclusion were not described by Students. Holly described correlational aspects of the campus’ physical and attitudinal environments that attributed to the ease with which she developed relationships with others. “It’s actually it’s a lot easier to get to know a lot of different people because it’s not as big as some of the other colleges around. There is a lot more close community and a lot closer people and get to know different people from different places and all that kind of stuff and you get to connect with them for different things.”

Students were also aware of the PSE program’s role in coordinating social interaction and opportunity. Recurring opportunities, such as weekly recreational therapy, as well as infrequent opportunities such as traveling to and presenting at conferences, were cited as

opportunities to develop or strengthen relationships. Holly described her experiences at one academic conference, “You get to connect with the people you already know. You get to know everybody just a little bit better. Yeah I met some people from the conference and then after the conference and after my presentation I had a lot of people come up and say, ‘That was good. Thanks for telling us about that’ and ‘That was really, really good so you should do that again sometime.’ So I got a lot of complements.” Students, each who followed weekly activity schedules which outlined times, places, and Supports, were aware of the program’s role in constructing social obligations as well as opportunity. Students were introduced to new peers because they were scheduled as natural Supports. Schedulers also provided support in planning social activities from attending sporting events to volunteering. These services were seen as valuable by some and burdensome by others, but in either case the PSE program’s role in the Students’ social lives was acknowledged.

### *Responses to Inclusion*

Students reported positive affect as a common response to inclusion. Varying degrees of inclusion evoked happiness. Some students described feeling happy with individuals or small groups of trusted friends who were often also Supports. For example, Emmanuel said, “Me happy in picture. I’m happy because Carla is my suitemate. Real happy. Friends. Because of friends” (see image 4.3). Other Students reported feeling joyous when reflecting on repeated activity and inclusion within formal (fraternities, clubs, etc.) and informal (‘lunch crew’) groups. Students also associated positive affect with the opportunity to be included in the college environment—a chance to prove their competency and worth to others. Joy said, “I feel like I belong at WCU’s campus. It makes me feel good to see like all

my friends and all my- all the people, and so I can show my mom and my dad that I am ok living by myself and stuff like that.” Happiness was linked in statements to elements of inclusion, belonging and being valued. These elements were described across spaces, activities, and social partners, and positive affect resulted.



*Image 4.3* ‘Emmanuel’ with his friend, Support, and suitemate, ‘Carla.’

### *Barriers to Inclusion*

Students described a few common barriers to inclusion such as a need for more social skill development and friendships that were contextually bound, such as relationships with classmates that dissipated upon exiting the classroom. The one common barrier, reported by most Students (5/6) was scheduling. When Students referred to scheduling as a problem that prevented social inclusion, they often spoke about two scenarios. The first was in reference to daily activity schedules. To assure that Students had access to adequate support across vocational, academic, and social environments, the PSE program created paper schedules

every week. Like a typical schedule, days formed columns and times of day were constructed in cells beneath the columns. In the cells, activity and activity location were displayed. For Students with lower literacy, symbols representing activities were included. Also, beneath the activity was a picture, name, and phone number for the Support when support was scheduled for the activity. Schedules were always completed in days leading up to the scheduled week. Preplanning weekly events became problematic when they conflicted with Students' desires to participate in unplanned activities. For example, Kelvin said, "I did want to go to one international fair on campus but it was like too late since schedules were already published." Echoing Kelvin's sentiment, Zeke described how his schedule prevented him from going to baseball games. "Like let's say if I have to cook. There is a [program developed] class for cooking and it is like after cooking...if the [PSE program] says I have to go to my dorm then I have to go to my dorm and then I can't go to a game." Schedules were constructed to reduce anxiety and provide support to assist students in navigating daily activities, however, Students identified the ways schedules limited desired social interaction.

Time conflicts were another way Students perceived schedules as social barriers. Activity schedules left blocks of time without support. In those times Students, if they desired, could try to arrange social meetings, often for meals, recreation, or leisure. However, Students described the difficulty of matching their free times with other students' free times. All college students have multiple obligations, especially during the day. Holly told how one of her classes was during a time when most of her friends were available to share lunch. "They're usually out there is at that time and I have to go to class. That's the only thing that prevents me from hanging out more than usual." Similarly, Kerri reported experiencing a

similar scenario, “[Support/friend] probably cannot [go to lunch] because she has a class she has to go to after. She has a lot of classes though...there are only like a few people that can eat during that timeframe. Everybody else is in class.” Desires for social interaction went unmet when Students’ schedules conflicted with the schedules of individuals with whom social interaction was desired.

### **Axial coding**

Where initial coding employed the constant comparative method to maintain a degree of reliability in the coding process, giving similar phenomena similar codes, the focused coding process elevated thematic elements of social inclusion which were interpreted as important for all Students. Though the aspects which made experiences unique to the individual were moved to the periphery, common experiences were compared and elevated to further develop the Students’ aggregate voice. The collective voice not only described social inclusion, it further described conditions under which social inclusion was strong as well as the times when inclusion was blocked. Categories and context had taken shape and axial coding further defined boundaries.

Axial coding was a pathway to further developing categories of social inclusion. In the axial coding process, focused codes were helpful in providing parameters to categorize initial codes as well as memos. Memos were written at all levels of analysis, beginning at interviews and extending from transcription, initial coding, and focused coding. Interpretations, comparisons, comments, and connections, ranging from sentences to paragraphs, were kept and eventually pasted into emergent categories that were beginning to



appear through focused coding. With codes categorized and blended with memos, explanations of categories could be provided.

The nascent categories and category descriptions are neither exhaustive nor mutually exclusive (Glaser, 1978). The categories are influenced by initial and focused codes, with significant overlap with the latter. Fittingly, most focused codes that were important for more than half of the Students became categories, including individual skills, contributing, membership, expanding social networks, and exclusion. Categories pertinent to the study of Students' social inclusion are presented below (see Table 4.9).

Table 4.9

*Student Axial Codes Pertaining to Social Inclusion*

Category	# of Initial Codes	Definition	Contributes to Belonging	Contributes to Accreditation of Worth
Individual Skills	286	Personal proficiencies utilized to promote and maintain social inclusion.	Yes	Yes
Connecting	143	Social cohesion, perceived as 'real', with individuals or groups.	Yes	Yes
Expanding social networks	101	The act or process of socially convening with previously unknown individuals or groups.	Yes	Yes
Friendship	129	Frequently occurring social relationships, from which all parties derive a sense of familiarity and emotional closeness.	Yes	Yes
Valued social role	174	A sanctioned function and/or identity within a given setting or context.	Yes	Yes
Campus climate	100	Attitudes, relationships, and structures in a college community that affect the functioning of embedded individuals.	Yes	Yes
Social barriers	80	Any elements which impede or prevent opportunities for social inclusion.	No	No
Exclusion	65	Perceived differences or lack of value which result in the denial of social access, opportunity, or participation.	No	No

*Individual Skills*

Students described their individual skills as a causal explanation for their opportunities to be embedded in the campus's social fabric. Some skills were unlearned including extroversion- a desire to interact with others. Holly said, "I just have a natural thing

to want to go over and meet new people but- it is just my natural instinct.” Most Students, like Holly, recognized the benefits of having alone time but preferred to spend their time in college interacting with others.

The desire for interaction motivated students to proactively organize social opportunities. Social arrangements required establishing meeting times and places and sending invitations through phone calls, texts, email, or Facebook. All Students at one point or another described the ways they used social and technical skills to reach out to college peers to maintain closeness where distancing was feared, or to organize social events. Sometimes Kelvin would use Twitter to seek social opportunities. “Sometimes if I’m alone I will Tweet something and connect and see what other people are up to.” Holly, alternatively, like others, preferred to use her mobile phone because it “helps me to connect with people on campus I need to talk to like my friends and my class supports... And it helps me stay connected, like if I want to do something I can call a friend and see if they are able to do it.” Kerri recognized that increasing her ability to contact others and arrange meetings would be beneficial to her social life. “I can also get more communication skills that way and learn how to connect with a few new people. I think it would be a really good learning experience.”

Some Students described how being socially proactive is more than arranging social opportunities, it is seeking and attending social opportunities arranged by other individuals or groups. Supports also provided assistance to Students to help them further discover social niches within campus. Zeke joined social activities with a fraternity, Holly stayed engaged

with a sorority, while Kerri and Kelvin engaged in clubs to build social opportunity. Seeking new crowds and making the most of social opportunities was described as necessary skills to become more active in the campus community, and many Students recommended that future students seek similar opportunities.

Another important skill that some Students had and others were developing, was the self-belief that they were competent enough to make decisions regarding social interests and obligations. This skill is referred to in codes as 'self-determination.' Partly, self-determination was an observation of one's competence and partly it became a request to increase control over one's daily schedule and social life. Kerri observed her increasing abilities to control her social life when she stated, "You can do anything. You can run, walk, you can take a picture...I made plans for alone time, homework time, and with some people too." Zeke also observed his increased control over his life and used an off-campus concert (see image 4.4) that he attended with a non-Support as an example of his self-determination. He said, "once you go see a concert basically it's like saying 'I'm an adult. I get to choose. I get to choose the things that I want.' And going to a concert is what I wanted. If that's how I feel about it then I want to go. And that is how I got to go." Self-determination was sometimes learned, sometimes given, and other times taken, and it showed a desire to be respected, trusted, and given more control.



*Image 4.4.* Zeke described his sense of control over his life when he attended an off-campus concert.

#### *Connecting/ Being Connected/ Membership*

Connecting and membership were combined to form a single category, belonging, because both described being part of a collective. Belonging, as earlier described, was interpreted as being a primary element of social inclusion. Belonging is a concept which is part affect and part declaration. Of the former, Students described feelings of belonging such as Holly's "I just feel included in groups" or Joy's "I feel like I belong at [college's] campus." Similarly, Students used variations of the word 'connection' to describe their perceptions of social inclusion in college. Membership, on the other hand, corresponded to consistent group engagement, and described the behaviors necessary to maintain membership. Kelvin for example, frequently described his membership in the Asian Students' Club, the International Club (see image 4.5), and the university's diversity committee.



*Image 4.5.* Kelvin, a member of the International Club, attended and photographed an International Fair event to describe his club membership and the campus's openness to diverse communities.

### *Expanding social networks*

Students described how their social networks grew. New relationships were built with new social partners, friends, or groups. Three primary network expansion catalysts were identified: 1) supports; 2) PSE Program; 3) oneself. Supports made permeable the boundaries of their social circles. Interactions between peers unfamiliar with the PSE program and Students were casually arranged, often when Supports invited typically developing friends to share social activities with them and Students.

Holly and Zeke described their Supports' role as social catalysts. Holly said, "We meet people through friends all the time! I met a girl yesterday I knew nothing about. She knew me though. She said, 'You're Holly aren't you?' I said, 'Yes.' And she said, '[Your support] talks about you all the time when she's with me, I know you.' (laughs). It's like we go around and people seem to know us because our Supports talk about us to their friends and their friends seem to get to know us and then their friends will start joining the support

stuff that they can do so they can hang out with us and get to know us better.” Her statement captures the ways network expansion began with Supports and ‘snowballed’ through the campus community. Zeke described how Supports validate Student worth to assure others of Students’ ability to belong with other college students. He said, a “Support has been with me for example and that person is saying to her friend or his friend saying that, ‘Man, Zeke is so cool. He is like spectacular. He is doing what he is supposed to be doing.’ That’s just for example and if that happens then that person makes that person want to be with me basically.” For Students’ social inclusion and network expansion, Supports were portrayed as having a critical role.

Students also viewed as inconsistently capable of growing their own social networks and needing assistance from the program in the process. In the first respect, students described how the program created schedules but how they collaborated in the process by meeting with schedulers weekly and detailing social activities which they wished to pursue with or without support. By expressing a desire to participate in Greek organizations, clubs, or committees, Students were able to attend functions with unfamiliar peers. The contact with non-Supports increased opportunity for network expansion. In other cases, Students asked for unscheduled or flexible time that could be formatted by one’s desires, such as the opportunity to share activities with non-Support friends. Nonetheless, the PSE program’s role in creating or restricting social freedoms was made clear. Sometimes Students met completely new people because they appeared as scheduled Supports, and sometimes these relationships developed into friendships.

## *Friendship*

Students needed evidence of friendship, and mere social contact was not evidence enough. Students regarded friends, as shown in focused coding, as peers whose interaction was repeated and with whom bonds were formed. Comfort, familiarity, closeness and commonalities were hallmarks of strengthening rapport. Kerri constructed a friendship typology based on frequency of interaction and familiarity. New Supports and others on campus who did not know her very well and about whom she knew little were labeled as “acquaintances.” But she went on to explain, “They become friends as you get to know them a little better and then they become best friends.” As familiarity and frequency of interaction increased, so did depth of friendship, not just for Kerri but for all Students.

Most students did not define friendship. Rather, they detailed social interactions with those labeled ‘friends.’ Kelvin described one of his friends through commonalities and connection. “Tricia and I always have a fun time talking since we both like a lot of international foods and stuff...we both connected because we both had an interest in international studies.” In friendships, Students felt invested in and valued. They also described the ways in which they invested in others. Friendships were not immediate and had to be earned by passing through stages contingent upon investment, commitment, trust, and comfort. Friends provided a stronger type of social inclusion. It is important to note that the majority of Students showed pictures of their Supports and named Supports when detailing their friendships. Support friendships were most common and further explained through theoretical sampling.



### *Valued Social Roles*

Students described their participation in roles society esteems. Two major components of social inclusion, as described by Students, were belonging and worth. Students understood their value when participating in certain social roles; therefore, Students shared their membership in valued social roles. Students framed their competence and value within five roles: 1) College students; 2) Employees; 3) Contributors; and 4) Adults.

Going to college in America has become a typical rite of passage from high school to adulthood. College provides the environment and opportunities for one to develop an identity as well as a chance to develop skills necessary to advance opportunity and accomplish life goals. Emmanuel connected his abilities to learn with an opportunity for upward mobility- a chance to “move up.” He said, “I like it up here college. Learn a lot. Classes and take more classes and up ladder. More classes...paramedics class.” Student roles were emphasized through describing dedication to studies, even when class and homework obligations were described as sometimes inhibiting social interaction. Joy showed photographs with classmates (photo-release was not obtained) to portray her literal fit among college students in college classes, while Kerri took photographs of her classroom to emphasize her role as a learner (See image 4.6).



*Image 4.6.* Kerri photographed her classroom to emphasize her role as learner and student.

Unemployment in the University's region reaches upwards of 20%. Jobs are something that most people want and something that each Student had. Through jobs Students were able to show their skills and gain responsibilities. And for some, like Emmanuel and Holly, jobs enhanced social experiences. Emmanuel described his co-workers' investments in him and his admiration for them. His co-workers were also his friends. Holly's work created the opportunity for expanded social contact; she said, "Well, I know in the [work] Center...I see a lot of students who come in there and I speak to some of them that I've never met before. And I know when anybody comes into the school and they come in the front way...and the [work] Center is the first thing they see when they come in. So, I see a lot of different people come in through those doors." Employee roles were connected with identity and self-worth. Employment required competency, contribution, and ability to participate in the economy.

Students described the ways they contributed to social relationships, making them bidirectional affairs. Embedded in the college experiences were multiple Student benefits, but they wanted to express how their presence benefited others too—they described their value to their community. Contributions were comprised of multiple acts. For example, Kerri described volunteering to clean a river that ran next to the community. She said, “You have to look for trash...we had trash bags. I was just holding the trash bag because it was muddy down there actually. It was like ‘ew, mud,’ so I was like ‘ahh, trash!’ And we had to keep our eyes open for trash.. Similarly, Emmanuel described volunteer work at food banks and with emergency responders. Holly described contributing to fundraising efforts for autism research, while Kelvin, Zeke and others described educating others through formal and informal opportunities such as presenting at conferences or teaching their peers about disabilities. Holly also described the response she received after presenting at a conference attended by practitioners, families of people with disabilities, and academics. She said, “I met some people from the conference and then after the conference and after my presentation I had a lot of people come up and say, ‘That was good. Thanks for telling us about that’ and ‘That was really, really good so you should do that again sometime,’ so I got a lot of complements.”

All valued social roles, Student, employee, and contributor, can be combined into one identity: capable adult. Students described themselves as people with the potential to make decisions and live independently. They described their reduced reliance on others and increased self-sufficiency. They did not just receive support, they showed they were useful and belonged in the campus community and could contribute to society in general.

### *Campus Climate*

Students perceived the campus as having an open and inviting social, attitudinal, and physical environment. Social opportunity was perceived as attainable and readily available, building Students' social confidence and mitigating social anxiety. College was viewed as a place where people were eager to engage a diverse student population. International students as well as students with varying cultural backgrounds, home regions, or areas of study, seemed to function together without conflict leading Students to see themselves as just another diverse student in a diverse student population. Zeke described the open environment in this way: "Anywhere I go to, when I walk, there are people that I don't know and they don't know me. They'll be like, 'Hey, how are you doing?' and 'What's your name?' You know, they're just very friendly. They just want to know who you are... And the students here, they really want to... be um educated to help [students with disabilities] and they really want to know new people." At the time of this research, the campus had fewer than 10,000 students, making Students feel closeness with peers. Students also described frequenting certain campus locations where opportunities for social engagement were concentrated. The University Center, dining halls, and recreation center (see *image 4.7*) were all emphasized as environments where they were included in social activities and social groups. With little evidence to the contrary, Students felt they socially participated in an environment where they were included. Most of the time they reported feeling like they belonged and feeling valued by their social peers.



*Image 4.7.* Kelvin described the Campus Recreation Center as an area of concentrated social interaction.

### *Social Barriers*

Social barriers were any element within a social ecology, from limited personal proficiencies to policy, which impeded or prevented social inclusion. The scope of barriers applied to Students' social lives was limited to their experiences. As explained in focused coding, Students most often mentioned a lack of control over one's social life which primarily manifested as a perceived inability to change daily activity schedules. But in other cases, an imbalance of social networks created social opportunity with one group while building barriers with others. A few Students described the same individual or group of Supports when describing social activities or social plans. Close relationships built codependency, and Supports became primary centroids in social networks, thus creating unstable social networks. When primary social partners were unavailable then Students were more likely to spend time alone. For some Students, families remained the crux of social networks, which reduced social opportunities. This was particularly true on weekends when family dependent Students would go home rather than experiences the challenges and

opportunities in the campus' social landscape. Busy weekday schedules allowed for little social time, but on weekends more casual time with others was available. Family time was an individual choice, but those who preferred it sacrificed the depth and breadth of campus relationships.

### *Exclusion*

Students described situations and contexts where they felt peripheral or outside of groups in which participation was sought. Students were more likely to recount the effects of exclusion, rather than the act of exclusion. Exclusion was a dependent variable, the result of various barriers to inclusion. They described situations where they were denied social access, opportunity, or participation, but rarely were these situations framed as the result of malice. Peripheral statuses, when Students were social outsiders looking in, were observed, like when Holly would participate in some sorority activities but was never extended the opportunity to become a member of the sorority. Joy and Kerri also described situations when Supports or classmates chose to hang out with *their* friends. The implication from such statements was twofold. First, friends had social spheres that did not include the Students, and second, Supports chose the social company of others before that of Students. In one case, Zeke described working on a class project with a group of classmates who neither invited his participation nor listened to his input, but descriptions of such cases were rare. Most often Students framed any lack of social inclusion as the product of misaligned schedules.

Students also made a distinct differentiation between exclusion and beneficial alone time. They described being alone but not lonely. Alone time was productive. For example,

Joy framed alone time as ‘calm down time,’ a chance to regain focus. She said, “I don’t like being by myself a whole lot but I like to be by myself sometimes. It is my calm down time. So I can like focus on what I am getting ready to do.” Kelvin echoed Joy’s sentiment by saying, “I like to hang out with people but sometimes I will just catch up on homework or just hang out.” Kerri described how alone time could be beneficial, especially when each activity in her day was accompanied by a Support. She said, “I still hang out with my friends even though I like to read. I might just need an hour for alone time...if I have leisure time I will just do whatever because I’ve been hanging with people all day.”

### **Theoretical Sampling: Process and Results**

Descriptions from more than twenty Student interviews combined with the researcher’s analysis and interpretation to form a coherent picture of social life on a college campus. Social inclusion was shown to have various forms, but always as a function of membership and assessed worth. A primary barrier, schedule conflicts, emerged as a real barrier to social inclusion. More often than not, however, Students felt included in a community comprised of familiar others, acquaintances, co-members, and friends.

The majority of the time peers labeled or described as friends were Supports. Some Supports knew more about the Students than others. 25 Supports held paid positions that were attained through experience with and dedication to Students and the PSE program. Every week paid Supports provided more direct assistance or indirect assistance as schedulers or suitemates. Of all typically developing students on the college campus, the paid Supports had the greatest knowledge of Students’ daily routines, experiences, strengths, and

limitations. For these reasons, paid Supports were invited to share through focus groups their interpretations of Students' social experiences in the college community.

Theoretical sampling is a process whereby presuppositions about phenomena can meet the scrutiny of individuals with knowledge on the phenomenon. More specifically, direct input through new data collection or analyses additionally refines categories. With the benefit of new insight or different perspectives, gaps, known or unknown, can be filled to better saturate categories. Saturation is when new data or analysis neither creates "new theoretical insights, nor reveals new properties" of categories (Charmaz, 2006, p. 113).

Theoretical samples often consist of additional data collection from a study's initial participants, but returning to the same participants is not a requirement. Social interactions require a minimum of two parties and with each party is a unique perspective on social occurrences. Frequently, social interactions occurred between Students and Supports or were observed by Supports. Therefore, when seeking more detail on Students' social experiences, paid Supports were the ideal group to clarify or complicate categories built from Students' social narratives.

#### *Description of the sample: Paid Supports*

Twenty-three undergraduates and two graduate students were paid to provide various types of support for Students. All paid Supports had a minimum of one semester's experience volunteering with Students, and all had received training to provide strategies and expectations for working with adults with ID. Additionally, each Support was required to work a minimum of ten hours a week providing some capacity of support in the college



environment. Most students were paid with funds from a PSE program grant, but some were paid either through federal work study or a local chapter of a national service providing agency.

Focus groups did not begin until after all Student photovoice interview sessions were completed. Preliminary concepts derived from Student narratives contributed to the direction of the open focus groups to which all paid Supports were invited and 15/25 (60%) attended. Of the three focus groups, one was comprised of three Supports while the other focus groups had six Supports each. All focus groups had one male Support and the rest were female Supports. All focus groups were conducted, recorded, transcribed, and analyzed by the researcher as to allow maximal familiarity with Support interpretations of Students' social experiences on the college campus. Analysis followed a similar process as the one applied to Students, except that attention was given to all elements of discussion which further completed categories derived from Student narratives.

### *Analysis*

From three focus groups 525 initial codes were constructed. All codes were added to an Excel spreadsheet and highlighted to correspond with the focus groups from which they were derived. A numerical value was assigned to each initial code to classify comparative codes, resulting in the construction 34 initial categories. Conceptual similarities across codes led to code consolidation. For example, code categories "Supports as friends," "reciprocal relationships," and "maintaining relationships" were combined to form a "friendship with Students" category. One theoretical code, barriers to inclusion, was immediately apparent.

Supports described a variety of ways in which Students' access to inclusive social participation was impeded. The other two thirds of codes described the relationship between Supports and Students or clarified conditions that, when present, made social inclusion more probabilistic. Memos and quotes from focus groups that described or explained the nuances of social relationships between Students and Supports were used to further explicate category boundaries. The interpretation of Support observations formed parameters for category definitions, which could be subsequently compared to Students' categories. Support categories are defined below beginning with categories that matched Student categories and finishing with novel categories unique to Support interpretations of Students' social experiences.

#### *Individual skills for social inclusion*

Like Students, Supports identified and emphasized individual skill sets, behaviors and capacities as contributing to social inclusion. Recall that Students primarily described how extraversion and the ability to coordinate social activities increased opportunities for inclusion, and on occasion Supports did the same. For example, a Support described how Students were being more proactive and actively engaging in the community. "This group of (Students) is so involved in intertwined with campus life. Like Kelvin, I don't know when he sleeps. He's done so much [with student clubs] and I know Liam [a student who chose not to participate in the study] works with or he did work with the athletics and that's really spread his social circle."

With few exceptions, however, Supports described the need for individual skill development rather than extant personal skills. Supports described ways which developing and refining personal and social skills could help Students further expand social networks and opportunities. One Support said, “I think we need to educate (Students) about how to start a conversation with people in your class, and say, “Hey, would you like to go have lunch with me or would you like hang out at the UC (University Center) one day?’ and then that can build on further relationships and friendships.” She went on to describe how Students needed to continue developing resilience when social invitations do not yield immediate results. “There needs to be a discussion of ‘Okay, you know, why didn’t this work out? Who can I ask next?’ because I feel like that when that [social rejection] does happen I feel like it just stops the reaching out for more friendships. They’re like, ‘Ok. I tried it. It didn’t work. Now I’m going back to my group of friends that I know and trust.’” Some needed skill sets described were personality oriented such as motivation for social participation and others were strategies commonly employed by others such as scheduling social interactions, joining clubs or volunteering, but Supports did feel that further skill development could enhance Students’ social experiences.

### *Expanding social networks*

Supports also described the ways Students’ social networks expanded. Particularly, Supports detailed the roles they played in adding breadth to Students’ social networks. Every Supports merged multiple social spheres by introducing people they knew to Students. These actions were ‘social support’ in the most literal sense, and Supports readily recognized their contributions as “catalysts” and “liaisons” to Student social experiences. One Support said,

“We as natural supports do tend to help jumpstart some of those friendships and kind of help clear the way a little bit for their friendships,” while another from a different focus group echoed the sentiment. He said, “Without us there [Student social experiences] wouldn’t be as inclusive at first or as fast as it does with the natural supports, ‘cause I do see the [social] network and [social] web. With the natural Supports they introduce the [Students] to more friends and then [Students] meet friends on their own.” As shown in the latter half of this statement, Supports did give Students credit for expanding their social networks with help from others. Students, in some respects, held a social advantage over typically developing peers because they gained immediate access to prefabricated social networks that other students might have to work harder to access or build. One Support viewed this process as a Faustian bargain, one that created quality social experiences while removing social development that occurs when individuals strive to build their own relationships—she said, “If I hadn’t been involved in the program...then maybe Holly would have never gotten involved with riding with the team.” Such statements served as a reminder of the tenuousness of all social relationships.

### *Open campus environment*

Like individual skills and network expansion, Supports confirmed the importance of the campus climate for Students’ social experiences. The category was the same but the ways the campus environment was described differed slightly. Students described an extant openness while Supports were more cautious at confirming a current state of openness. Instead, Supports found the environment to be transitioning to more acceptance for diverse populations, including students with IDD. If the campus was not ‘open’ it was receptive to

learning more and taking steps to assure all students were included in the campus community. No one in the campus community took an outright stance against Students' inclusion. But, Supports recognized the novelty of the intellectual diversity brought by the Students. There was no history of including students with IDD, and consequently, no script for inclusion existed. Education and innovation were required, especially by more formal campus groups, such as fraternities and sororities. One Support described a fraternity's efforts at organizational learning saying, "It's not that they were opposed to it. It just hadn't been done here before so part of it was 'Well, what's it going to look like?' ... it was more of figuring out 'Well, how do we do that? We've never done it before.' And they worked it out. They're learning. I mean, they've never done it before." Fraternity brothers had to learn how to provide natural Supports and ways to make sure Students were safe and respected. Similar examples held true for classes, clubs and committees. Open campus was directly related to expanding social networks, exposure and awareness.

Instructors and Students were also described as creating an inviting environment where Students treated like their peers. In academic courses the inclusion of non-traditional Students required deliberate efforts by instructors and classmates. While many Students did not mention the classroom as a place of social inclusion, a Support described classes as inclusive, "I thought in that class she was included, like perfectly. They treated her like I was treated, like it was the same. ...like if you would have not known who Joy was then you would have thought that was just normal. She was treated equally, I thought, in that class. And even in that class, with like discussions you know, if the teacher was calling on people who weren't raising their hands, like I would get called on and she still called on Joy, you

know. It wasn't like every time. You know, [the instructor] included [a Student]. [The instructor] just didn't let [the student] sit there.”

Supports described how on the campus, formal environments were first to enhance a culture of social inclusion. Administrators, instructors, and club and fraternity directors were early adopters and advocates for an inclusive campus culture. One Support said, “[the University] has made some improvements, but I think they've made improvements with like the staff of [the University], like the chancellor, you know, the [Student] work (places), the people over the different departments for work, the professors and not so-- I mean, we still have a long way to come, but I feel like we've made more improvements with those individuals than like with the students at [the college]. While campus inclusion may have not be dictated from the 'top' down, Supports sensed that was the general direction of movement with informal, student groups being the last to make efforts to socially include Students. From Students' perspectives, peers created the open environment that contributed to perceptions of acceptance and inclusion. Both Students and Supports' descriptions detailed a campus environment that could be defined as in between 'approaching inclusive' and inclusive.

### *A Scheduled Existence*

Supports detailed a number of barriers to Students' inclusion, but only one barrier, scheduling, strongly overlapped with Student observations. Students described situations where they were unable to socially participate either because social partners had other obligations or because daily schedules restricted participation in chosen activities. Supports

bolstered sentiments. Each focus group separately identified a resultant lack of social spontaneity as the single major flaw of Students' activity schedules. The typical college experience, as described by Supports, was one where social events were rarely premeditated. Events were mostly "spur of the moment." Any social preplanning, if it existed, was minimal. One support said, "they do have that very intricate detailed weekly schedule and so a lot of times I'm scheduled for them to eat. That's different from a lot of my friends where most of the time when we get together to eat it is more spontaneous. I typically don't plan to eat with a friend [next week] on Friday [of the previous week]."

In contrast to 'typical' experiences, Students' social activities were planned a full week in advance. Having approximately 14 hours of back-to-back planned activities was not uncommon for a common day. From 8 A.M to 10 P.M. students were busy with academics, work, meals, and developmental requirements, placing strain on social experiences which often had to co-occur with scheduled events, such as meals as Students described. Supports saw Students as living "scheduled existences" which prevented social spontaneity and increased perceptions of their differentness. As one's differentness or otherness is emphasized the strength of their social inclusion is diminished. As a Support described it, with "the [Students] it has to be scheduled out. It has to be planned out. You cannot decide to take them somewhere at ten o'clock at night because they must be somewhere (else) at a certain time. And so that's one area that I see the friendships are different. Like it is almost a scheduled friendship even though it is a friendship there are schedule times when you can hang out or certain things you can do, so." Differences in 'life-flow' created different types of friendship—a different type of inclusion. In this sense, the social effects of Students'

activity schedules, not the schedule itself, created significant barriers to Students being fully included in the campus environment. Detrimental effects included a lack of social spontaneity and a lack of control over one's daily routines.

### *Exclusion*

The final category with considerable conceptual overlap with Student social descriptions was exclusion. Only the results of exclusion were documented by Students. They described situations where they felt on the periphery of social groups where membership was desired, such as Holly's peripheral relationship with the sorority which was also noted by Supports. Students also described situations where they felt lonely, though more often than not 'alone time' was viewed as a desired commodity. Paid Supports, through hours of contact, described a keen awareness of Students' exclusion, and not just the product of exclusion—Supports described others' actions that resulted in Students' exclusion.

One action which emphasized Students' otherness was staring. Though Supports may be more aware of instances of staring, its implications for otherness and social exclusion ultimately had an effect on the prospects of Students' full social inclusion. A Support described staring as an act of exclusion. "It frustrates me when I'm with the [students] and I'm eating dinner and people are just staring. I wouldn't want someone watching me while I ate, and (I) feel like a sideshow, and that's kind of how I feel it is because people are sometimes just staring and laughing at what is going on and it is just frustrating."

In other instances, Supports recognized their role in perpetuating Student exclusion. Although Supports were dependable when they were scheduled by the program to interact



with participants, there was a sense that many Supports did not prefer to interact socially with Students when it was not required. These preferences resulted in Student exclusion and negative affect. As Students attempted to independently initiate social activities, the risk for rejection was greater. Meals and weekends were where Students often began assuming more control over their social lives, and Supports described the outcomes that sometimes resulted. One Support said, “I went up there with Zeke and saw Kelvin by himself... That’s heartbreaking because you know he’s probably tried to call somebody or there is somebody he knows up there for sure who just didn’t want to eat lunch with him, you know.” Another described independent weekend scheduling, a “[Student] was trying to fill in his weekend schedule for this upcoming weekend and he was just really bummed about it because everyone he talked too was like, ‘Aw man, I’m busy. I don’t know what I’m doing.’ That’s very hurtful to them and he was pretty down in the dumps because [Students] want to hang out and do things just like we do.” Another Support in the focus group added that “people are like, ‘Friday night I don’t want to go hang out with a [Student].’ And like [another Support] said, that is really hurtful to them to feel like they don’t have anybody who actually wants to hang out with them.”

While Supports presented several variations on exclusive actions, one more type was mentioned across focus groups and created a sense of consternation when discussed. Supports found Student intragroup exclusion particularly troubling. One Support described recreational activities where Students chose teams and inevitably they always chose other Students last. Supports saw this as evidence of the implicit construction of a social hierarchy among Students. A Support further described the phenomenon, “It’s like where ‘Yes, I know

I have a disability but I know my disability isn't as bad as this person's disability and I don't want to be seen with them because I'm better than them and I can do more things than them and this person with a disability that is worse than mine hinders my ability to do things.' And I think that's where a lot of that comes in, and it's like, yes we need to educate the community of [the University] but we also need to educate [Students] about including everyone as well." In sum, Supports agreed that there were time when Students were socially excluded. In addition to stating the existence of social exclusion, they portrayed processes of differing by people with and without disability as culpable for exclusion.

Students and their Supports similarly described or explained Students' social experiences. Both parties were in agreement that 1) Students' personal skills helped create and maintain social relationships, 2) Students' social networks expanded while in college, with Supports often serving as social catalysts, 3) Students' weekly activity schedules reduced opportunities for casual and spontaneous social interaction, and 4) Students, for a variety of reasons, did experience, on occasion, social exclusion. Where categories converged, Support perspectives offered an extension of Student descriptions. In other cases, Supports contributed novel descriptions of Students' social experiences and new explanations for Students' inclusion or lack thereof.

The section below is comprised of novel categories that emerged during theoretical sampling. Because Students described their social experiences as interwoven with their relationship to Supports, elements which better explained the Student-Support social dynamic were treated preferentially. The categories, however, are not limited only to the

social dynamics between Students and Supports and include additional Support identified barriers to Students' social inclusion.

### **Theoretical Sampling and Novel Categories**

#### *A different kind of friendship*

Two-thirds of Students described campus friendships that were almost entirely with Supports. Supports were considered “friends” and even “best friends.” In all Support focus groups the sentiment was stated in the opposite direction—Supports said they viewed Students as personal friends. However, Supports, unlike Students, described caveats in the friendships. Students were friends, but a different kind of friend. As one Support put it, the friendship between Student and Support is “just a different relationship, I think. It’s not that it’s negative in the way that it is different. It’s just different.” Students described Supports/Friends as dependable, familiar, helpful, and nice, and each characteristic was similarly conveyed by Supports. But, there was more to the narrative. Despite expressed dedication to Students’ quality of life and overt claims at the ways that relationships with Students enhanced their lives (“sometimes I think I show more of my real self with [Students] than I do with some of my other friends. It’s just-- I know they’re not going to judge me. They’re not so worried about some of the things that some of my other friends are worried about, is freeing I guess.”), Supports were unable to view or treat Students like their college friends without IDD. Social relationships with Students were viewed as nonequivalent to social relationships with ‘other’ friends.

The partition of friendships into Student and non-Student typologies was largely due to role conflict. As one Support said, “You do have the balance between ‘I do work for the UP Program’ and ‘I am your friend’-- that fine line.” Friendship and Support roles cannot coexist without one role affecting the other. To provide high-quality support, Supports felt that they had to build the rapport and emotional closeness often associated with friendship. It was no accident that Students viewed the actions and intentions of their Supports as evidence of friendship. To provide superior Support meant viewing relationships with Students as “more than just a job.” As one Support explained, “You want to check up on this person and you want to know how they’re doing in their homework or talk to them during the meals and see how their lives are going because it is more than just a job. Like, it is a way of life. It is a part of my life because I want to make sure that their life is the best it can be.” Despite the intentions, the ability to fully dedicate oneself to either a ‘friend’ or ‘support’ role was impossible.

Role conflict did not affect the value Supports assigned Students. But, in terms of social inclusion, the segregation of friendship types did diminish a Students’ belonging, after all if one does not belong with one’s friends where does one belong? The separation for friendship occurred through differences in activities and behaviors. Even when they were not formally assisting Students, Supports attempted to model behaviors that they felt would most reduce risks to Students’ development or physical health. In short, Supports did not take the same social liberties with Students that they did with others. They avoided crude humor. One support said, “I do filter what I say around them because I know I have to continue to stay on a professional level as well. So I really can’t be inappropriate with them as I might with some

of my other friends.” Though most Students had reached the age to legal consume alcohol, Supports would not go to bars or drink alcohol with Students. “I guess with our friends that are not associated with the program, we can do things like go to the bar on Thursdays or whatever or pick up and road trip to Asheville out of the blue but we can’t do that with the participants...it is more or less the professionalism of it. There are some lines that you just wouldn’t cross regardless of what you were doing for your job, with like employers and fellow employees, customers, consumers- there’s just lines that we can’t cross even though we do consider them our friends.” Supports avoided other behaviors or activities that they believed morally or socially questionable. Instead they opted for “positive recreational” activities. “I feel like we can go sit at the fountain with a [Student]. Like that is something I’m comfortable with doing and I feel like it is fun or going to play disc golf or something like that. I guess it is positive recreational- that kind of stuff that I feel comfortable say that I’d do with them versus having a movie night with a glass of wine. I would feel like uh uh (no), she don’t need to do that.” Supports separated their friendships into two groups: Students and non-Students. In the former, a sense of duty determined behaviors and activities in ways the latter friendship were not affected. Balancing friendship and responsibility proved challenging for Supports and made their social relationships with Students different from their other relationships.

### *Watered-down Inclusion*

While Supports readily admitted that their friendships with Students were different than their friendships with other peers, they did not question the authenticity of their friendships. Supports did, however, question whether certain types of social inclusion were

real or fake. When Students were not perceived as being included or excluded in ways that their typically developing peers might experience, social inclusion was deemed “fake” or “watered-down”. Fake inclusion was described as temporary niceties or placations—when social partners play the role of interested friends but interest vanishes when activities cease. Supports differentiated real and fake inclusion with theatrical terms: “There shouldn’t be like this “ok, we’re going to include [Students] now. They’re going to come to this activity and everybody is going to act normal and it is going to be like there is no difference.” It has to be just something that happens, you know what I’m saying? There shouldn’t have to be any me setting the scene before it happens.” If inclusive relationships were reduced to roles played temporarily, then social inclusion was not considered authentic. Omitting behaviors and activities, such as those removed for different types of friendship, was more permissible than creating behaviors and activities that in order to manufacture an image of inclusion.

Watered-down inclusion was a concept described in relation to Students’ development. When natural Supports were trained they were told to provide assistance when asked or needed but to otherwise allow Students to face environmental challenges and solve problems as independently as possible. By contrast, watered-down inclusion was inclusive situations where the Program or Supports assumed too much control, thereby limiting the opportunity for Students to develop in the most natural contexts as possible. The Support who originally used the term “watered-down inclusion” described the phenomenon this way—“We also talk about making adaptations to where [Students] can do [activities] too. But I feel like when we make those they’re so obvious and so different to where they still feel like, “excluded because you made it so obvious that you changed the activity, but I’m still

included.’ You know? And you kind of like water it down so they have the watered down inclusion.” When Students gained access to larger campus events but continued to be surrounded by individuals associated with the PSE program, Supports deemed such situations watered-down social inclusion. Even though some Students shared desires for more independence, their social narratives never declared experiences of social inclusion as watered-down or fake, nor did they share the sense that the friendships they had forged with Supports were different from any other friendship.

### *Barriers: Awareness and Exposure*

Beyond contributing assessments of Student relationships and the quality of Students’ social inclusion in the campus community, Supports also shared three barriers to Students’ social inclusion that had not been mentioned by Students. Using photographs, Students started with very concrete descriptions and moved to more abstract concepts such as “friendship” and “connection.” However, photographs only once led to conversations outside individual and relational realms. In that case, Kelvin described how the Universities across the country could create programs that would be more inclusive for Students with ID. Supports did describe how families, the program, communities, and mass media affected Students’ opportunities for social inclusion. Exposure and congregation commonly mentioned barriers.

Lack of awareness was described as a barrier in general and specific terms. Many times Supports felt that their peers did not know the university had either students with ID or a program that facilitated their participation on campus. Supports felt the PSE program

needed to do a better job at creating a brand. They felt if others knew about the Students and the Program then there would be fewer negative interactions and a greater desire among peers to participate in Students' lives. They also felt Students would gain more legitimacy if others were more aware of how Students gained access to the University's academic, leisure, and social environments. Supports felt that by increasing awareness and exposure to people with different intellectual abilities, typically developing students would exhibit more respect and less anxiety with Students. All Supports admitted to experiencing elevated anxiety around Students when they first started volunteering. After building familiarity and creating relationships, Supports began to see Students as more similar than different which is consistent with growing social inclusion. One Support said, "People who are volunteering with them for the first time are like 'I have no idea what to do!' I'm like, 'They're just like a regular person. Like just go eat with them. Do homework with them.' I feel like society has put up this image that people with disabilities are scary or they're uncharted territories and you won't understand how to handle them when they're just like everyone else." The barrier, as Supports saw it, was a lack of awareness or exposure which resulted in increased perceptions of Students as different and not belonging on a college campus.

*Barrier: Congregation*

In addition to scheduling, needs for personal skill development, and a lack of awareness, Supports felt that situations where multiple students shared the same space at the same time had detrimental effects on inclusion and future inclusion. This instant was provided by a support, "I kind of feel like when we do activities- what was it, the dance at the



fountain, the flash mob? All of the [Students] were grouped together and then in the front. Like you stick out like a sore thumb because it's like so many people out, spread out, and they have friends you know, well maybe [a Student] wants to sit somewhere else! But, they like always are together and they may not want to be." Congregation, as the Support described, reinforces ideas that people with disability should have social networks primarily constructed of others with disability. Additionally, such social groupings modeled disability as a grouping trait and thus reinforced negative stereotypes. More personally thought, Supports observed several participants who were not comfortable being grouped with others, but their schedules created circumstances under which they were supposed to participate in such settings. Also, some Students do not identify with the group and prefer to not be congregated. In that way Students' social inclusion was affected, or as a Support said, "I think inclusion would be letting [Students] do their own thing and not having them come together."

### *Summary*

Chapter 4 directly addressed research questions. Quantitative and qualitative results from three methods and three response groups described Students as seldom lonely or excluded. Within the college environment Students experienced degrees of belonging and belongingness. Attribution of worth also varied. Students described their competency and engagement in valued social roles, but Supports reported cases where others in the community focused on Students' differences and limitations. The results, nonetheless, were interpreted as evidence of Students' social inclusion. Social inclusion, comprised of variables and contexts, were also variable and different types were associated with different types of

social opportunity and breadth of network. Primarily, however, data presented social inclusion occurring within and from shifting social dynamics between Students and Supports. The interrelationship simultaneously exhibited closeness, care, and confusion. Supports promoted and prevented sustainable social inclusion. Whether reliant or independent, Students framed their social location in reference to Supports. Supports described deep set affection and value for Students, while admitting to fabricating inclusion. Social inclusion is primarily about relationships because it requires a minimum of two people, but the main relationship that emerged in this study was the one between Students and same aged, natural Supports. Further discussion and interpretation of results is provided in chapter 5.

## CHAPTER 5: DISCUSSION

### Introduction

Social narratives from Students and Supports delivered through questionnaires, photovoice, and focus groups converged with researcher interpretation to construct statements on Students' social experiences. The purpose of this chapter is to further explore constructions of social inclusion. Another level of abstraction, grounded in Student and Support data, was added to formulate a social inclusion theory for students with ID in the college environment. The theory describes social inclusion and how it varies by contexts. Later in the chapter the theory is referenced in suggestions for changing PSE program procedures to further advance Students' sustainable social inclusion. The chapter ends by comparing social inclusion definitions and categories with the literature, describing limitations, and discussing directions for future research.

Upon embarking on this research, little was known about the social experiences of college students with intellectual disability. Postsecondary education programs described Students college experiences as 'inclusive' or 'fully inclusive' without providing evidence for the claims. Social inclusion has been considered a primary domain of quality of life, and yet little was known about social inclusion for college students. This study trained Students to collect data and create meaning to state whether they were socially included. Data were also contributed by college age natural supports for triangulation of Student social experiences. Knowledge, co-created, was intended to be used to make college more inclusive for intellectually diverse students.

## **Grounded Theory of Social Inclusion and Inclusion Typology**

The grounded theory process included Student interviews and Support focus groups. The data were analyzed through a common coding process to introduce active and descriptive categories of Students' social experiences in the college environment. Supports expanded on Student categories and added new categories. Categories and the narratives that produced them were contextually situated in an interactive setting with the researcher. Participant comments were interpreted to construct a theory for social inclusion in the college environment.

### *Social Inclusion Theory*

All Students experienced social inclusion in college. They described a variety of ways in which they belonged in the campus community and were attributed worth. When students belonged in groups ranging from one social partner to many, their commonalities were more socially influential than their differences. Similar interests and life experiences grew friendships and strengthened group cohesion.

Supports explained how Student belonging expanded through repeated contact. Their anxieties decreased and they started to identify Students as belonging—students were described as “regular” people who were “just like everybody else.” Increased levels of acceptance, along with identifying shared values, interests, goals, and identities were all indicators that students belonged in a given social context, and when they participated in selectively permeable social activities, Student's enacted their membership.

Through surveys Supports also reported that students rarely, if ever, experienced loneliness, which can partially be conceptualized by a lack of belonging. Where loneliness was absent, belonging was more likely to exist. But, belonging was not always easily described or directly observed, it was also explained as sensation. Students perceived themselves as “part of something bigger” and feeling connected to individuals, groups, and the campus (superordinate) community. Students’ emotional needs for acceptance were attained by belonging, whether or not the construct was perceived.

Recognizing social partners’ inherent value is axiomatic for social inclusion. Beyond basic human rights, one must be viewed as capable of contributing to social relationships. Acknowledging one’s social contributions, individual strengths, and other qualities worthy of admiration builds the possibility for reciprocal relationships where no single individual has their needs met without meeting others’ needs. Worth attribution consists of values (as discussed), beliefs, and behaviors. Worth is expressed when one is appreciated, respected, and invested-in for who they are and what they can contribute. Worth is exhibited when choosing to interact with an individual when social alternatives are available. By inviting someone to participate in social activity and introducing someone to other social actors, one’s behavior expresses strong attributions of worth. Attributed worth and self-worth function reciprocally and both were requirements for social inclusion.

The theory advances a notion that social inclusion is more than just a static composition of belonging and attributions of worth-- it is a dynamic function of the situational co-relationship between belonging and attribution of worth

(Social inclusion =  $f[(\text{Belonging})(\text{Attributed Worth})]$  Context). Belonging and Worth are mapped on to social inclusion but the formula is only conceptual, not operational. The interlaced relationship between belonging and worth, within context, creates social inclusion. Social inclusion is not constant; it varies with roles and social groups and is continually redeveloped in each social situation.

As social relationships develop, more worth is attributed to social partners, and as partners are viewed as capable of dependently reciprocating to meet group needs and requirements, social bonds grow stronger. Changes in worth have associated changes in belonging and vice-a-versa, such that membership can neither exist in the absence of attributed worth nor inversely relate. While attributing strong value to someone will not make them a group member, it does create a strong opportunity for membership if the individual assessed as worthy chooses to participate. To gain membership, an individual must have an assessed worth approximately equal to other social members. With nuance and context muted, the relationships between belonging and worth follows this approximate logical pattern:

- 1) All people who belong in my group are valuable
- 2) I belong in my group
- 3) I am valuable

When this logic is mirrored for others a process of social inclusion initiates which follows the same logical pattern by co-relating belonging and worth:

- 1) All people who belong in my group are valuable
- 2) Student X is valuable
- 3) Student X belongs in my group

Steps 2 and 3 can be continuously transposed until one exits the group or loses their attributed worth. The model requires a degree of equality to be perceived. One group member's value should be approximately similar to other members' values though the reasons for attributed worth might widely vary.

All final concepts, generated through interpretation of Student and Support data, including personal skills, expanding social networks, valued social roles, connecting, barriers to inclusion, friendship, and exclusion all fit into the social inclusion formula, as will be described below. Because concepts are broad they could realistically have elements which contribute to multiple aspects of social inclusion. Students' personal skills are connected with one's attributed worth and belonging. For example, when Kelvin would text, call, Skype, or Tweet others to "catch-up" and maintain friendships, he was using technology mediated communication to meet friends' emotional needs and increasing his social value. Twice a week, Kelvin would contact friends and meet them for lunch. Eventually the group of individuals developed a name for their informal group: "the lunch club." Through organization and consistent participation, Kelvin's membership in the "lunch club" was solidified.

When Supports helped Students expand their social networks they were attributing worth to Students. The act of introducing two previously unfamiliar individuals is an expression of value-- it is a belief that each party has something to offer the other. Similarly,

Students described how unfamiliar others would introduce themselves and state that they heard positive things about the Student from a Support who was a mutual friend. The Support described Students' value which created the opportunity for membership and social inclusion.

Students frequently described the ways they participated in valued social roles such as a volunteer, conference presenter, college student, or employee. In each of these roles, Students' importance had been validated. Their participation in working with others to accomplish goals increased their self-attributed worth and the value attributed by others. When value was perceived opportunities for membership increased.

Students described feeling connected with individuals, groups, or the university as a unifying superordinate structure. In these situations students detailed the extent to which they perceived themselves as belonging. When peers invested time and emotional energy into relationships, Students felt closer to the investor. Placing one's resources into another's wellbeing is an act committed for those of assumed value. The connection students felt was a byproduct of feeling valued and feeling like they were part of cohesive groups.

Not all concepts strengthened social inclusion. The Students and Participants mentioned barriers to inclusion. Stereotypes, unfavorable attributions of worth associated with membership in a categorical group such as "people with disabilities", can lead to exclusive beliefs and values. Congregation was viewed by Supports as supporting beliefs of otherness born from stereotype. If the stereotype, for instance, was people with disability are



unable to maintain friendships with those without disabilities, and then Students were observed only with others with disability, then the stereotype is reinforced.

The lack of prolonged social interaction between Students and most other college students also contributed to the maintenance of negative attributions. Believing Students are not capable of meeting another's social or emotional needs increases the likelihood that Students will be denied membership. Supports felt that others on campus, without interacting with Students, were unable to view commonalities as exceeding differences. Without close interaction there was no chance to dispel myths. Lack of awareness or exposure damaged opportunities for social inclusion.

Other categories mentioned by Supports and Students resulted from the relationship between belonging, worth, and context. Friendship, for example, was an example of social inclusion with a strong presence of membership and inclusion. However, the types of friendships reported shifted in accordance to context. Students described feeling comfortable just "hanging out" with others who were perceived as invested, familiar, and similar. Supports alternatively, described familiarity, reciprocity, and dependability as instrumental to close relationships with Students. However, Supports did not benefit from the same levels of comfort as Students. Supports felt it necessary to avoid some activities and discussions with Students that would compromise their support role. Within Student-Support relationships different friendships existed. Both types had allowed for belonging, worth, and reciprocity, but in the inclusive friendships primary roles were not congruent. Students viewed themselves as friends who were socially involved with other friends while Supports

viewed themselves as role models—as professionals with friendly relationships with Students. The separation of roles and differences of power allow for an inclusion where Students are valued but different. Membership and attributed value were not balanced, but friendship remained. Social inclusion appeared in many forms depending on contexts and social actors.

Social exclusion was also the product of belonging, worth, and context. Exclusion emerged as a category from Supports and Students, but instances were described as fleeting rather than systematic. Theoretically, complete exclusion would require the absence of belonging and attributed worth in a given context. However, such scenarios were only once described in the data when Zeke felt like a member, by name only, of a class project group. He described being silenced because his group did not value his input. He felt near the group but not part of them. For the most part though, students described contexts in which their participation was limited; their membership was not strong nor did they feel strongly valued, but neither variable was entirely removed.

Similarly, Supports described multiple situations when students had been ‘excluded’. When Students were alone in places, such as the dining hall, or at times, such as the weekend, Supports attributed the aloneness to Students’ not being valued and not being seen as members of a social relationships or group. Sometimes, inclusion and exclusion even shared the same space. As friendships were enacted in the social and physical foreground, distal acts of exclusion were given little attention and often had no emotional repercussions. Supports caught others variously staring, ignoring, or laughing at Students, a production of

social differing. But, those types of exclusion were distal and occurred while students simultaneously were engaged in activities with ‘friends’. Being valued and included in one context eclipsed co-occurring negative judgments. Multiple views on membership and Students’ value can occur within the same social context but all can be accounted for in the social inclusion function.

### *Context, Social Inclusion, and Social Capital*

All categories fit into the social inclusion function, but some are better explicated within the contexts of students’ inclusion. First, of note, this segment responds directly to research questions by functioning within the premise that all Students were socially included in college during the time of the study. Seldom was strong evidence of exclusion presented. At minimum, Students experienced social inclusion of varying strength across social context, but mostly, students described different types of inclusion. This section will better explain differences in social inclusion.

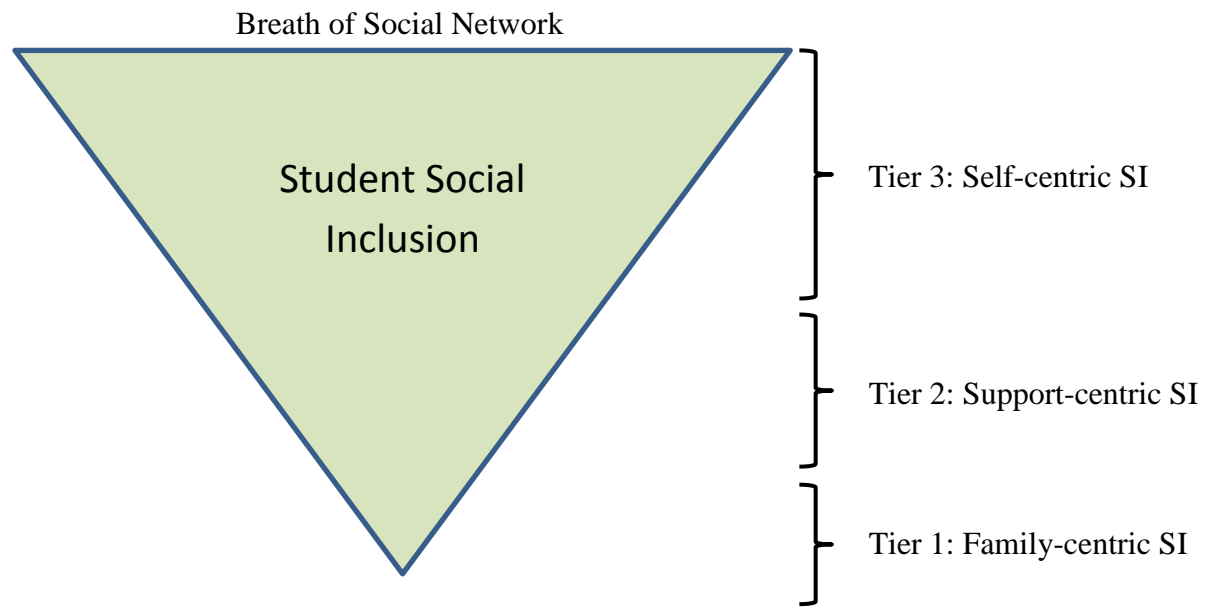


Figure 5.1 *Typology of Inclusion Contexts*

Figure 5.1 is an inverse pyramid equally filled with color that represents Students' social inclusion, as present across contexts. All Students were socially located within the pyramid's boundaries, meaning all were socially included. All Students were spatially included with access to college classes and facilities, and all Students were cognitively and emotionally connected to the same superordinate group: the university. All students donned school colors, cherished the mascot, and identified as students of the specific university.

The pyramid's inverted base represents breadth of students' social networks. A student's vertical location within the structure represents the size of social networks. Though social inclusion is perceived by students at all points, students with more expansive social networks gained more social opportunity (i.e., social capital) and social choice.

Brackets on the pyramid's right side are arbitrary but serve as approximate signifiers of tiers of social inclusion. Again, students were socially included within all tiers, but social inclusion and social networks were primarily, but not exclusively, facilitated by family in the first tier and supports then oneself in subsequent tiers. Across tiers, breadth of social network differs, but social inclusion within social network is achieved. Based on the social inclusion function and regardless of tier, Students belong and are attributed worth. Tiers were a context in which types of social inclusion occurred, but they also co-created contexts in which social inclusion of varying strength occurred. A more in depth discussion of tiers describes how social inclusion varies based on the relationships with and roles of primary partners in one's social network.

### *Tier 1*

When social inclusion was primarily facilitated by family members, Students experienced little danger of being treated categorically instead of individually. Family members were familiar with Students' strengths and positive qualities. Families have made assessments of a Student's worth and fit. Siblings, parents, and extended family members were dependable social partners.

Students who were physically closer to their families maintained increased social interaction. Weekends were primarily spent engaging in social activities with, or facilitated by, adult family members. Families also wanted to see students, but time away from campus prevented opportunities to build depth in friendships and breadth in social networks. Inclusion in Tier 1 was dependable and left little risk of social exclusion. In the short term,

such comfort has positive effects on quality of life, but over the long term good intentions of people bound by blood or duty constrained social development and limited social capital. Having social experiences either planned or mediated by relatives or caretakers is an experience with which most college students would not identify. Those experiences are differing and can be perceived compensation for dependencies, thus weakening chances of belonging and perceived social worth outside of the small, closely bound social network. While the close bonds in Tier 1 need not only be with family, such relationships were most common for Students, who like their peers, were transitioning from high school to adulthood.

### *Tier 2*

Opportunities for social transition are more available in Tier-2 than Tier-1. A new environment and increased physical distance from parents, guardians, or care takers increased social exposure and social risk. As in Tier-1, social networks in Tier-2 were frequently facilitated, but quality of life remained intact. Danger of categorical treatment was low, but increased social encounters, both fleeting and repeated, prevented complete protection. Connections to a superordinate group, in Tier-2, remained intact.

Facilitated social experiences, even within larger social networks, create social dependencies. Authenticity of inclusion was also most scrutinized in Tier-2. Social stage setting manufactured an atypical inclusion—one to which typically developing peers would not be exposed. Supports felt like overly constructed social context misled Students to inaccurately assess belonging.

Furthermore, interactions in Tier-2, like in Tier-1, could be spawned from obligation or choice. In both cases, supports treated students well, thusly fulfilling the worth aspects of social inclusion. But, Supports have other objectives which are not purely social. Those objectives- to help, protect, and educate- require friendships to be separated into Support and supported. In dichotomies defined by power belonging is finite. When Supports' obligation outweighed friendship, Students were less included, but when Supports performed friend roles, risks of social dependency increased. And while social reliance on same age peers does not result in the same stigma as those who do not naturally belong in the college environment, too much reliance hampers one's abilities to form social relationships.

Tier-2 created contexts which either reinforced social helplessness or increased social independence. In the latter case, social learning occurred directly and indirectly, and Supports introduced Students to individuals and groups who were not associated with the PSE program. Desires for more social choice, independence and opportunity to display social competence was essential for Students in Tier-3, but until they were ready Tier-2 served as a social training ground.

### *Tier-3*

Campus community based inclusion, most present in Tier 3, created more access to varying groups that were neither constructed as a guise or for the benefit of Students alone.

Membership in groups had to be sought and accepted. If Supports appeared in groups it was because they would have naturally appeared in group activities regardless of a Student's presence. Social resources were accessed through membership. Individuals in Tier-3 build a

social resume which can be reviewed as validation of social worth. Membership in one social group, led to friendships, which increased the opportunities for further network expansion. In Tier-3 social dependence decreases and interdependency increases.

Social risk is also greatest in Tier-3. The likelihood one will be judged by their disability increases as protective buffers from supports or family are removed. Social networks in Tier-3, primarily with Supports, created as safety net. In cases of exclusion, an alternative social network was available. By taking risk and straying from social equilibrium, those in Tier-3 have the broadest social networks and have the best chance to accurately assess social skills, as well as membership and worth in an open social ‘marketplace’. Rejection, implicit or explicit, may be more likely but when close relationships or group memberships are constructed they will be solely on perceived merits. Assessments are more accurate because “fake” inclusion or “watered-down inclusion” is less likely in Tier-3.

### *Tier, Power, and Sustainability*

Students’ social experiences can be summarized through the social inclusion function. Through membership and by being attributed with social worth, students were socially, not just physically, included. The factors that applied to Students’ social inclusion are likely foundational for anyone’s social inclusion.

Types of inclusion formed and were formed by social contexts as shown through the inverse pyramid of social inclusion. Broadly, Students’ social context could be captured within the pyramid scheme. Joy and Kerri’s social experiences were played out in the



transitional regions between Tiers 1 and 2. Kelvin, conversely, was transitioning into Tier-3 with all the other Students between these poles, socially located at various points within Tier-2. But, all typically developing peers can identify with social inclusion contexts, some depend more on family to meet socio-emotional needs. Some students, like those in fraternities or sororities, relied on more safe and predictable, group facilitated social experiences, and others likely went beyond the reaches of a group's social network to seek membership in a variety of interest-based sub-communities. The social inclusion theories may not be generalizable but they are generally relatable.

Several social barriers such as a prescheduled existence, needed skill development, or lack of exposure weakened social inclusion. Moreover, barriers exerted downward force within the inverse pyramid, making transitions from one Tier to the next more arduous. Social challenges make appealing the safety of dependable social networks, regardless of why or with whom networks are formed.

Students experience varying power dynamics within different tiers. In Tiers 1 & 2, though Students were included and were treated well, they participated in asymmetrical social relationships. With friendships and other types of inclusion where some are viewed as caretakers of any sort, and others are viewed as cared-for, the split roles form power differentials. Instructors, mentors, advisors, or role models have ulterior obligations and motivations that serve as the impetus for formed social relationships. Though friendships may form, they are "different kinds of friendships". A high quality of life can emerge because relationships between caretaker and cared for often contain compassion, familiarity,

dependability, and protections from social exclusion. But, caretakers always maintain a degree of authority and that they know more and know better—their expertise fills gaps between another person’s functioning and environmental demands. When social dependency forms in Tier 1 and Tier 2 relationships, students are more likely to defer to others to meet social needs and miss important developmental and social opportunities in the process.

When Students organized social activities, solved problems, and took risks, they refined social skills. However, participation in college, by way of a PSE program, created different social contexts than just college participation. Program graduation required Students to meet weekly criteria for academic, vocational, personal, and social development. Meeting these criteria required extensive activity schedules. Also, Students had access to instant social partners through paid and volunteer supports. Schedules and peer aids were structured to help students meet environmental demands. The PSE program structure, however, inadvertently created social dependencies. Students could rely on Supports to participate in or schedule social activities leading to social inclusion, and when they did, an acute quality of life may have come at the expense of future quality of life. When students had fewer opportunities or less need to create their daily schedules, choose their social activities and their social partners, and exist within socially ambiguous environments, opportunities for learning transferable social skills decreased. Students’ college experiences are two years. Two hundred Supports are unlikely to help facilitate social inclusion after graduation. For the sustainability of social opportunity and inclusion, Tier-3 provided the best chances for finding inclusion in ways consistent with community inclusion. The alternative is to return to Tier-1 social inclusion where social networks are fragile and could quickly dissolve when

dependent partners, such as parents or siblings, can no longer facilitate inclusion. Thus, while social inclusion and accompanied quality of life were available throughout the inverse pyramid, students Tier location mattered for power and sustainable inclusion. Paradoxically, when Students became more independent, exhibiting more social choice and control, they acquired more social relationships while decreasing the likelihood of “watered-down inclusion.”

### **Discussion of Results**

*What does the study mean?*

Initial descriptions of Student social experiences were sought and obtained. No single Student was always maximally included at all times or in all contexts. No narrative from Students or Supports was identical. Social inclusion was dynamic and unstable. It did not simply exist or not exist; it came in degrees because it was a product of three variables—belonging, attributed worth, and context. With the exception of a few notable dimensions (i.e., ‘watered-down inclusion’) Student experiences mirrored social fluctuations observable among late adolescents living in a college community.

Despite descriptive challenges, Students and Supports shared social experience narratives. They described sub-parts that collectively formed social inclusion, and they described barriers to inclusion. Observations were infused with identity. Students had roles that extended beyond their colloquial namesake in this study. Besides students, they described themselves as employees, researchers, presenters, friends, advocates, and contributors. Most often, Students described themselves as competent adults with the skills

needed to build and maintain a social network. Supports, conversely, described bifurcated roles. They were friends and care providers though the latter often took precedence. Assisting Students, paid Supports said, was more than just a job, it was a way of life. They described how they connected to Students and cared for them in ways that other students did not or could not. The experiences, infused with identity construction, were interpreted into a description and theory of social inclusion for college students with ID who lived and learned on a college campus.

Most Students attained a degree of social inclusion the majority of the time. Amidst great detail, vagueness was introduced by the importance of context. Students could experience strong social inclusion with one group of peers in some spaces and elsewhere could be perceived as less competent making them more marginalized. The belonging and attributed worth within any context determined the strength of cohesion with social counterparts. Belonging was when Students' commonalities were viewed as greater than their differences. Comfort was indicative of fitting-in. Others' estimates of students' ability to contribute to a social situation, as well as Students self-worth, contributed to worth. Environments, relationships, and attitudes all co-created belonging and worth to form relative amounts of social inclusion in any given situation. Social inclusion was always relative because one social experience could be compared to another but no absolute measure of social inclusion exists.

Given that social inclusion was a theoretical function of belonging, attributed worth, and context, the strength and type of inclusion were susceptible to change. Strength was

altered with closeness of relationships and opportunities to contribute in meaningful ways to social partnerships. Inclusion types were broken into tiers depending on the contexts through which social experiences were facilitated. Social networks primarily organized by family members or guardians were defined by fewer social experiences. Opportunity, social capital, and network breadth were also limited, though it was entirely possible for strong perceptions of social inclusion to exist in this type of inclusion. Alternatively, when students were the primary agents of their social endeavors they were able to test elasticity of social networks and seek friendships through multiple social arenas. Between the two context types, was a type defined by social experiences planned by supports or programs. More opportunity and social capital exists than in social networks constructed by families, but fewer than if one were master of their experiences. The bulk of described social experiences occurred within the Tier-2 social context type where supports were most responsible for social networks.

The presence of social inclusion, defined by belonging, worth, and context, was equally accessible in each facilitation type. Strong social inclusion was possible even if one's social experiences were planned entirely by support aids. Different context types, however, confront PSE goals, sometimes with conflict.

PSE programs vary greatly in structure and pursued outcomes, but most try to increase student independence and opportunities for competitive employment. Of the 149 PSE programs surveyed by Grigal, Hart, and Weir (2012), 34% indicated that the primary focus of the PSE program was independent living skills, and 32% said it was employment, indicating a strong focus on skills most associated with typical adult experiences. All college

students are expected to develop in some capacity while pursuing a college education. For Students the developmental goals were more overtly stated. The PSE Program provided literacy, financial, personal, and adaptive skills training to Students—training not available to typically developing peers in the college environment. Training was individualized, targeting challenges specific to each Student to promote skill acquisition and functioning so Students would live independently after their college experiences. Transitional training created a divergent college experience for students with ID, but it was a calculated trade for future quality of life.

Social narratives, however, identified gaps in training. Students viewed themselves as active, connected, and valued social participants in the college community, but often social inclusion existed within a Tier-2 context, meaning that supports and programs either facilitated or constructed most social experiences. Students benefited from quality social experiences at the sacrifice of development, choice, and future quality of social life. In social domains, training was limited. Quality of social life in college was not proportionately outcome oriented to the same degree as other training domains. Facilitated social experiences eliminated struggle, mitigated loneliness and reduced the risk of hurtful interactions, but it also kept students in positions of social dependence, detracting from independent living outcomes. Social narratives echoed the quality of current social experiences and implied the sacrifice to social development, social capital, and self-determination.

As previously observed for individuals with ID, social networks remained relatively small and mostly comprised of family and paid workers (Clement & Bigby, 2009). In the

college environment, family and paid workers were substituted for by college-age natural supports, paid and volunteer. Quality of social life and experiences of social inclusion were not sacrificed, however. Students perceived themselves as valued and socially connected with close friends and the larger superordinate group that was constructed through enrollment in a common university. Understanding of Students' social experiences in college was the primary goal, and the goal was accomplished, but experiences and interpretations of those experiences were embedded within specific scenarios. Experiences shared by Students and Supports cannot be generalized to experiences for students with ID in different PSE programs, nor can they be assumed to hold for the same six students in post-college communities.

*How well do results answer the research questions?*

A dearth of data detailed the impact of college opportunities for students with ID. Little was known about student experiences, much less social experiences. The design and methods implemented in the study created opportunity for Students to describe their social lives, networks, and lived experiences, and through the process research questions, were addressed. Research questions asked "How do Students and Supports describe social experiences of students with ID in the college community?" and "Do social descriptions provide evidence of social inclusion?"

*Supports*

Beyond Student activity schedules, little was understood about Students' social experiences. The PSE program claimed to be 'fully inclusive' but no evidence had been

collected discern whether students were socially included. While survey data were unable to provide any definitive ‘proof’ of full social inclusion, they did begin to address the stated research questions by showing that Student social experiences were not defined by loneliness. Survey results showed Supports believed that Students were not lonesome. Lonely individuals crave meaningful social interaction, but are denied the privilege. Lonely people feel excluded from social experiences accessed by others—they are isolated and their social and emotional needs go unmet by others. While the absence of loneliness is not equivalent to social inclusion, it does provide initial evidence about the quality of Students’ social lives. Supports stated, with little variability across respondents, that if Students ever felt lonely in college, it was a rare occurrence. Infrequent loneliness described positive social experiences.

Moreover, Supports viewed Students as socially supported. Lunsky (2006) viewed the presence of social support as equivalent to positive social relationships. Through the survey, Supports stated that Students had friends with whom they frequently shared life’s joys and pains—friends that reliably exhibited social and emotional closeness with Students. Survey responses addressed research questions by describing Student social experiences in college to be positive, defined by friendship and social connection. The descriptions suggested that the college social environment need not be defined by difference and exclusion, meaning college provided developmental opportunity and quality of life. Colleges were not doomed to replicate traditional special education short-comings, such as segregation.



Social narratives described in the surveys were complicated through Support focus groups. Students confirmed that the majority of times, Students participated in positive social relationships which gave rise to positive social experiences. Students were similar to their peers in that they had consistent access to social experiences that fulfilled their needs, but the path to that state was described as considerably different from college peers'. First, unlike their peers, Students' friends often held a position of authority. Supports were friends but also trainers and mentors responsible for shaping student development through suggestion, criticism, and encouragement. Relationship dynamics were not founded on equality, and in that way Supports described the friendship with Students as more different in expectations and requirements than friendships Supports held with others in the campus community.

Differences in Student social experiences were also defined by the contexts that surrounded social experiences. In short, Supports described the propensity for Support facilitated social experiences to be unnatural. Students were addressed with exaggerated enthusiasm and social scenes were prefabricated to disproportionately cater to student needs. Social attentions were concentrated on those in the social group with disabilities. Outside of ritualized ceremonies such as birthdays, weddings, and graduations, same-age individuals participating in a social situation should strive to equally distribute social attention throughout the group. Concentrated social attention on one social participant in a group, outside of ceremony, is commonly reserved for children. Therefore, 'watered-down' or unnatural inclusion, though resulting in a sense of connection and satisfaction, stripped Students of their equal social standing and even their dignity. Students may have felt a sense

of belonging in such social situations but attributed worth was lowered and social inclusion weakened.

Students' daily activity schedules directly affected social inclusion. Students described abilities to arrange social meeting through phone calls and texts. They described how to set places and times to meet and how to select activities to share with social partners, but most often Students' social encounters were planned approximately a week in advance. The PSE program planned the time of days when students ate, studied, exercised, and retired for the evening. With the exception of university dictated class times, typically developing peers in the college environment independently dictated activity and social schedules, and they, unlike Students, reserved the power to create and change social plans without requiring approval or confirmation. Students were not afforded opportunities to assert similar control over their daily lives, and social experiences were dissimilar as a result.

### *Students*

Support surveys and focus groups described, in detail, student social experiences and processes that facilitated Students' social lives, including what set them apart from other students in the campus community. Students' also directly described college inclusion. Photovoice provided user-friendly methods for students to describe social experiences with sufficient detail to determine whether they were socially included. Through interviews students described activities in which they participated. The diversity of activities ranged from ballroom dancing, and rock-and-roll concerts, to hiking and fundraising. Most commonly emphasized activities were "hanging-out" and sharing meals, both which were

defined by less task-orientation and more social interaction. Students, who were scheduled to transition between compulsory activities for up to fifteen hours a day, relished activities that permitted relaxation and relationship building. In such activities, Supports were more likely to accentuate the friendship aspects of their dual friendship/mentor roles, which led to more equality among relational peers. Students described themselves as competent and included in ways that they did not necessarily achieve in academically or vocationally oriented contexts.

Students emphasized social activities in which they felt most competent and built stronger relationships, and similarly Students emphasized roles which held higher status. They framed themselves as competent adults who contributed to the betterment of the community. Their role in educating others about disabilities to build comfort and reduce stigma was stressed as were situations where they solved problems or organized events. Though disputed by Supports, all students commonly framed themselves as primary actors and decision-makers.

It was clear that the photovoice method was an effective vehicle for students to directly describe their social experiences and the degree to which they were included. As represented throughout chapters 4 and 5, students told their stories and created identities for themselves that they wished to share. Through answering the research questions, students became the individuals they wanted to be. Participation in research was also an intervention that definitively transferred power to Student researchers. Students described and enacted their social inclusion.

### *Mixed-Methods*

Research questions were also addressed by merging results from multiple methods. An initial convergence of data occurred through theoretical sampling in the grounded theory process. Often theoretical samples come from the same population that initially participated in data construction, but it is not a requirement (Charmaz, 2006). Through theoretical sampling, a conceptual validation was sought for Student narratives. When commonalities were not bound to one particular method or sample, more confirmation was present. As discussed, Supports and Students shared common categories. Both groups, across two methods, described the importance of personal skills to build and maintain social relationships. Both also described the importance of a receptive campus climate, processes for expanding social networks. A common barrier identified by Supports and Students was an overly scheduled existence which restricted Students' choice and social spontaneity. All commonalities were not bound to one method or sample.

Whether or not common descriptions were presented, all methods contributed to understanding by building a more comprehensive perspective of Students' social inclusion on a college campus community. Supports described inclusion barriers never mentioned by Students, such as the ill effects of 'watered-down' inclusion, social congregation, and the community's lack of awareness and comfort with intellectual disability. Divergent insights would not have been obtained through a single method.

Quantitative results converged and contrasted with qualitative data. Unlike the open structure of interviews and focus groups, questionnaires limited the scope of Support

responses. Qualitative groups were provided opportunity to discuss any relationship, process, or experience that had an impact on Students' social experiences. Survey respondents were limited to describing whether Students were lonely and if they held supportive friendships.

Student interviews and Support questionnaires shared common perspectives, but only superficially. Survey results reported that Students rarely experienced loneliness. Similarly, Students reported rarely feeling lonely. To not be lonely, students were described as having a supportive friend network. Students frequently described themselves as participants in close friendships. Students such as Emmanuel, Joy, and Holly also overtly described having what they perceived as a surplus of friendship—an expansive social network. Both social support measures, however, emphasized the ways Students were supported by friends. Students, on the other hand, inverted Support emphasis. What could not be captured through surveys was the degree that Students supported others. Students emphasized the ways they contributed to their community's wellness; surveys emphasized the ways the community contributed to Student wellness. Even when results between surveys and Student interviews converged, they varied in scope and depth.

Survey scope was also limited when describing Student friendships. Friends were described as frequently available and supportive. Questionnaires could capture presence or absence of supportive friendships, but the method was unable to capture friend identities. Students and Supports most often described Students' friends as sharing common identity—they were also Supports. The questionnaire's aim was for Supports to share their opinions and assessments of Students' social lives. All social assessments provide opinions on at least

two parties, in this case Students and unnamed friends of Students who created a buffer to loneliness and provided emotional and social support. Supports' quantitative responses not only claimed Students had good friends, they also shared a belief that Students were embedded in an open and supportive climate. Focus group conversations qualified these assumptions. While paid Supports deemed the campus making progress towards openness and inclusion, they felt such characteristics were primarily associated with administrators, faculty, and Supports, a group that in aggregate account for a relatively small sample of the campus population. Paid Supports also described the majority of Student social and emotional support as coming directly from Supports and not the broader campus community. If friendships were mostly limited to individuals who were Supports or introduced by Supports, then the questionnaire was limited in its ability to comment on the campus community's social climate. The survey was unable to disambiguate Student friendships between Supports and non-Supports.

Through questionnaires, paid and unpaid Supports both agreed that Students had friends, frequent support when needed, and were seldom lonely. Students described frequent time alone but they did not contradict Support survey results. This is because for Students, time alone was not equivalent to loneliness. Students viewed alone time as constructive and necessary to balance the stresses of a busy schedule. When alone, Students found opportunities to relax and pursue activities of their choice such as reading, dancing, or listening to music. Even when physically alone, Students described themselves as socially connected through mobile devices and social media.

Paid Support focus groups, by contrast, were more likely to depict Students as lonely. Paid Supports described images of sullen Students dining alone or unable to find social partners to share leisure activities. The intragroup differences in opinion are not as contradictory as they appear. Supports viewed themselves as Students' primary friends, and the questionnaire asked for Support opinions about Student friendships and support provided by friends. Supports used surveys to simultaneously assess their success at providing quality assistance and Students' access to Supports' friendship. In focus groups, paid Supports had the opportunity to describe their support quality and contrast it to the community's limited contributions to enhancing Students' social experiences. Students described the importance of an open campus environment that made it easy for them to make new friends and feel included across multiple contexts, and Supports agreed that a PSE program would not work without community efforts of inclusion. Nonetheless, Supports underemphasized the community's role in providing social and emotional care. When Students were in need of support or wanted to actively participate in social activities, Supports viewed themselves as dependable partners who met the majority of Student needs.

### **Implications**

PSE programs at colleges and universities in the United States are differently structured. Organization varies along criteria such as on-campus living opportunities, vocational training, access to college-level courses, access to financial aid, and access to college facilities. Another element that contributes to programs' structures is the way typically developing peers are utilized. The spectrum of support extends from none to a lot. The PSE program in which the study's participants were engaged relied heavily on paid and

volunteer peers. While instrumental support such as transportation, assistance using money, or taking notes in class was integral to meet Student needs, the PSE program was also structured so Supports became socially involved. The PSE program's website outlined qualities of a volunteer which included characteristics such as "flexibility, dependability, and responsibility; showing you care and wanting to be involved;...having fun but remembering to be a good role model". For students, frequently involved and caring individuals, such as the Supports, were often viewed as friends, and based on Support focus group remarks, paid Supports viewed Students as friends too. By encouraging Supports and Students to become friends, the PSE program's structure was able to obtain enough volunteer hours to dependably meet the needs of Students with ID who lived in the college environment. Forming bonds between Students and Supports helped keep Students safe and navigate new challenges, all while permitting the program to function as envisioned.

Friendships between Students and Supports were to be expected. Adults with ID have "commonly" labeled service providers as friends (Marquis & Jackson, 2000), and some service providers described the close relationships as enhancing the enjoyment of work (Johnson, Douglas, Bigby, & Iacono, 2012). While the PSE program groomed Support/Student friendships, many social networks for individuals with ID have been described as primarily consisting of peers with disabilities, family, and paid aides (Cummins & Lau, 2003; Clement & Bigby, 2009). The social networks were often small too (Clement & Bigby, 2009). This study posits that the size and quality of social network is associated with the individuals who control and compose the networks. Whether family or Supports influence social relationships, social inclusion can occur, but different contextual tiers (tier-1:



family facilitated social inclusion; tier-2: support facilitated social inclusion; tier-3 self-supported social inclusion) provided different social opportunity, and the PSE program's structure created barriers to the most self-determined tier.

One barrier emerged as a result of the power differentials between social actors. Individuals with ID have been characterized as being more likely to agree with others, especially those in power (Snell & Luckasson, 2009). Typically, most social interactions with others without disability occurred with people who hold a position of power (Welsby & Horsfall, 2011). Such observations held true in this study, because Student social networks were largely comprised of Supports who held relative positions of power. With Support suggestions, Students were expected to comply. Student obedience was regarded at least as important as Student choice, but was emphasized more frequently. Students reported several instances when they complied with weekly schedules, even when schedules did not emphasize participation in desired activities with desired social partners. The option to make impromptu scheduling changes was never mentioned by Students or Supports.

While the PSE program relied on cohesive social relationships between Supports and Students, supports often reported role confusion. They were unable to simultaneously manage the duties of a typical friendship while remaining a responsible mentor and role model. To cope with the PSE program's dual expectations, Supports invented "a different kind of friendship"—the positive, social relationships they formed with Students were not congruent to friendships with typically developing friends. With "a different kind of friendship," Students' power did not grow and social dependence remained. What initially

was implemented to assure fluid and safe college experiences, created situations contradictory to student development and independence goals. One's access to power is exemplified through opportunity to develop skills and make choices affecting one's well-being, and what is more, obtaining power is necessary for strong social inclusion (Prilleltensky, 2010).

When services, such as the PSE program, take significant responsibility in planning Students' social schedules, then they are culpable for processes that contribute to social exclusion (Clement & Bigby, 2009). The PSE Program and Supports cannot build friendships for Students, but they can reduce barriers to Students independently creating lasting and reciprocal friendships. Some preventable barriers mentioned by Students included congregation, unneeded natural support, and few opportunities for social spontaneity. More emphasis needs to be placed on inclusive social climates and Students' training and development. When Students are able to independently grow friendships and expand their social networks, they have more access to social inclusion and social capital (Bates & Davis, 2004). Choice and self-determination must be valued more than obedience, so Students can obtain a Tier-3 inclusion and the enhanced quality of life with which it is associated (Cummins, 2005). Therefore, PSE programs are encouraged to develop program structures that minimize the role of non-disabled staff and peers in fashioning the social experiences of people with intellectual disability.

### *Striving for Tier-3*

Adults with mild ID will benefit most from PSE opportunities that purposefully shift away from social reliance contexts. Tier-1 and Tier-2 social circles are associated with restricted social networks (Lippold & Burns, 2009). By opposition, as the grounded theory of inclusion context proposed, increased social self-reliance should lead to expansion and diversification of one's social network and the associated privileges. While breadth of relationships can increase, depth can as well. Cummins (2005) noted that the presence of a caregiver, a Support in the PSE context, makes intimate relationships less likely.

While it might be obvious that when people have few chances to make their own plans they are more likely to feel socially excluded (Abbot & McConkey, 2006), future social inclusion and quality of life is also at stake. Without opportunity to learn how to make and maintain multiple friendships, Students will continue to remain socially dependent after graduation in community settings. Small social networks, especially those reliant on aging guardians or support staff, are less stable and at greater risk for network collapse and the resulting social isolation (Lippold & Burns, 2009). Individuals given chances to make independent decisions tend to exercise more control over their personal lives (Stancliffe, Abery, Springborg, & Elkin, 2000). Similarly, individuals with ID become more self-determined and exert more control over their lives when contexts permit them to do so (Wehmeyer & Garner, 2003). Therefore, if PSE programs provide Students with more opportunity to control their social experiences, they will become more eager and adept at individualizing their social experiences to best meet their social needs.

### *Improving PSE Program Procedures*

Students and Supports equally described, intentionally or not, needed changes in PSE program procedures. Changes are most needed to procedures that restricted students' abilities to create and change their social schedules. More emphasis on developing skills necessary to build and maintain social relationships was also needed.

Perceptions of PSE program effectiveness typically depend on Students' employment outcomes. Employment is an optimal end state around which to build program procedures. In addition to employment, independent living is a desired outcome, and it requires development of adaptive behaviors. One subset of adaptive behaviors includes the social actions needed to build and maintain social relationships. What this study showed was that development of social skills and control over social activities will be important for building future social networks and finding social inclusion long after exiting the college community. Future quality of social life cannot be sacrificed for social comfort during college.

Under support-manufactured inclusion students are less prepared to be the architects of their social experiences. Access to campus opportunities, spaces, and activities do not vary greatly between a Student who independently accesses social opportunity and one who does not. However, a Student's ability and confidence to contribute to community construction is affected by their inclusion tier. Agency is affected because Tier-3 inclusion most closely matches the social situations one encounters living independently in their community. Access to 200 supports is valuable for safety and creating an initial surge in social opportunity, but it is not something Students are likely to find outside of their campus communities. PSE

programs are charged with reducing social reliance on Supports. Future quality of social life will be more dependent on Students' abilities to be architects of their social experiences rather than their ability to remain obedient, and PSE programs will need to reflect the shift in emphasis in stated goals and procedures.

### *Probing social capacity*

One way programs can assist Students is by trying to assess students' capacities for building social opportunity. Capacity has been defined as "the ability to perform...a mental, cognitive, or intellectual task" (Wehmeyer, 2013, p. 252). Programs need to extend such definitions to understand a Student's abilities for performing social tasks required to either expand or deepen social relationships. Tasks for testing social capacity should include one's strategies for setting and accomplishing social outcomes. Take the social objective, for example, "I want to go to an off-campus restaurant with friends." To successfully accomplish the social goal, students must successfully navigate a series of steps including 1) identify friends; 2) identify a method to contact friends; 3) contact friends with an invitation that includes a time and date; 3) coordinate transportation; 4) arrive on time to a jointly decided location at a jointly decided time; 5) engage in a mutually beneficial social experience that satisfies one's and one's friends' needs and expectations, increasing the likelihood that similar meetings will occur in the future. Programs can create training experiences that locate Students' strengths and limitations in creating social opportunity and individualize educational approaches to further develop Students' abilities for performing given social tasks. Training opportunities also occur naturally, and Supports must be better trained to

allow Students to attempt and sometimes struggle to solve social problems or accomplish social goals.

### *Support training*

One's state of functioning has been defined by the discrepancy between one's capacities and environmental challenges (AAIDD, 2010). Some individuals require more emotional and instrumental support while others need direction and strategy. Support can be viewed as an accommodation which does not inherently alter expectations, but enhances access, physical, cognitive, or otherwise. Supports provide assistance to reduce the gap between abilities and challenges, but the ways assistance is provided directly contributes to Student development. Therefore, programs need to be maximally cognizant of how support is given to make sure development takes priority over efficiency and comfort.

As an example, refer back to the social objective "I want to go to an off-campus restaurant with friends." Students can attempt to independently accomplish this goal. Supports need to be trained to identify any stages of social goal accomplishment that students are unable to independently accomplish. Rather than solving problems for Students, Supports need to use any gaps between abilities and situational demands as a "teachable moments". By allowing Students to struggle with problem solving before providing support and teaching strategies for social goal accomplishment, Students will be better prepared to sustainably address challenges to social inclusion.

Access to skill development decreases when Supports assume responsibility for solving social problems. By preplanning trips to restaurants, to continue the example

previously used, or by completing some or all of the steps in problem-solving heuristics, Supports render Students impotent. When social planning is always done FOR and not WITH individuals then inability is presumed which creates a disabling contexts and lowered expectations. Assistance, in such a fashion, strips Students of the opportunity to learn and develop. Moreover, when social contexts are created or dictated by Supports (i.e., Tier-2), then programs are less able to accurately gauge Student social capacity—it is less clear what students are feasibly able to accomplish for themselves.

PSE Programs need to devote more time and resources to training Supports to provide social planning opportunities, assess social strengths and limitations, and implement strategies to assure students are learning to develop skills to sustainably enhance their social experiences. When PSE programs promote dependence, whether intentionally or unintentionally, they are not helping Students successfully transition from high-school to adulthood. The study showed that Supports were often responsible for most aspects of Student inclusion. Providing support in such a way prevented Students from acquiring the skills to sustainably create and enhance their social experiences. Therefore, PSE programs, to improve student development, need to view Support as equally critical as they view accommodations, medications, and safety (Bates & Davis, 2004). Assistance for meeting environmental challenges need not detract from Student development.

### *Disrupt Social Equilibrium*

A “scheduled existence,” one where Students’ daily activities are perpetually planned and aided by Supports, aims for social equilibrium, a state that exists primarily in inclusion

Tiers-1 and 2. Bates and Davis (2004) showed adults with ID as less likely to experience growth in competence when their experiences were mediated by caretakers. Similarly, Students experienced inclusion and quality of life when their social activities were preplanned, but their social competence was left in stasis. Limits of ability cannot be probed in environs absent of challenge, and knowledge of Students' social capacities cannot exist without disruption to social equilibrium. Therefore, for students to continue to develop and to increase the likelihood they will construct sustainable social networks, PSE programs must recognize when their social interventions no longer promote development or enhance individual functioning (AAIDD, 2010).

One way to disrupt social equilibrium and enhance Student development is to allow Students to have more control in creating weekly activity schedules. After graduation Students will be expected to contact community members and organize social activities, so opportunities to refine such skills should begin early. Similarly, Students need more control to make extemporaneous changes to scheduled social activities to accommodate inclusion in activities not planned more than a week in advance. With more control over social activities students would have more opportunities to engage with non-Support peers and participate in activities not typically considered by the PSE program.

#### *Eliminate Watered-down Inclusion*

One way natural Supports could contribute to changes in PSE programs is by not facilitating 'watered-down' or 'fake' inclusion. Such events, Supports described, were coordinated in ways that departed from experiences of college peers. Some events were not



age appropriate; others were coordinated by the program, requiring attendance from some social participants who would otherwise not choose to participate. Students regarded these experiences as validation of inclusion, popularity, and breadth of friendship, but the events were manufactured specifically for students with ID and were atypical in the college environment. The effects of participation in such events were positive affect and affirmation, but subverted efforts at identity management. ‘Forced’ or ‘fake’ inclusion, in addition to being deceptive, does not reinforce the commonalities and capabilities of college students with ID. When belonging and worth are damaged, ‘watered-down’ inclusion tends to create effects opposite from those intended—students become more socially excluded. When one is included by ‘actors’ without fully understanding that they are participating in an act, then their inclusion occurs with significant compassion but little dignity. Therefore, PSE programs and supports alike should strive to assist Students in experiencing college as similarly to their typically developing peers as possible. After all, Students do not receive separate curricula or have different access to campus resources, and their social experiences and opportunities should also be equivalent to their peers.

### *Support Variation*

Supports are any “strategies, resources, and activities that enhance human functioning” that can offset personal limitations (Wehmeyer, 2013, p. 253). The PSE program in this study provided a unidimensional approach to support. Strategies, resources, and activities, to a degree, were embodied within same aged individuals. Aid existed so much through individuals that those aides became known as ‘Supports’. This type of support, however, is evanescent- it vanishes with the individuals to which it was originally attached.

Strategies, alternatively, should follow the individual from one context to the next. Therefore, in the interest of sustainable functioning and social inclusion, programs need to shift conceptualizations of support away from typically developing individuals and towards strategies for accomplishing goals and accessing resources. Actively addressing policy also makes resources and activities easier to access for all individuals. Shifting inclusion types emphasizes the move away from social contexts pieced together by other individuals to one that emphasizes community openness, attitudinal change, and the supportive strategies so adults with ID have the best opportunity to live as architects of their desired social experiences.

### *Inclusive Evaluation*

For four weeks, Students evaluated their social experiences in college. Indirectly, students evaluated Supports, the PSE program, and the University's social climate. Students were similarly trained and all showed comfort using photographic devices to capture visual details of their lives, which Students did reliably. While Students had wide differences in cognitive and communication abilities, all actively engaged in constructing meaning from data they collected. Through interviews, they shared their social experiences. What students showed was that despite being labeled as having mild to moderate intellectual disability, they were fully capable of research participation.

Because students with ID can participate in evaluation, they should be given the opportunities and means to do so. Research participation benefits adults with ID. They have been shown to acquire senses of pride and empowerment (Jurkowski, 2007; Conder, Milner

& Mirfin-Veitch, 2011; Kramer, Kramer, Garcia-Iriarte, & Hammel, 2011). Moreover, when they are engaged in research and the decisions made from research results, adults with ID are less likely to be harmed (Clements, Rapley, & Cummins, 1999). Students are also the primary stakeholders of PSE programs; they are experts in knowing about college experiences for individuals with ID. Students also have the most to gain from successfully run programs. By engaging student voices, PSE programs will build student capacities and reconfigure programs to best meet Student needs.

### *Increased Risk*

No student who attends college is entirely immune from risk. But PSE programs embedded within institutes of higher education take precautions to increase safety and mitigate risk for students with intellectual disability. To stay safe, Students are required to own and know how to operate mobile phones, they are trained in safely navigating campus, and they have access to multiple supports and staff. For PSE programs to remain sustainable, Students must remain relatively unharmed. If PSE programs brought accident litigation to their universities, programs would be short-lived. Nonetheless, all college students with ID deserve the same dignity of risk afforded to their typically developing peers.

To deny Students risk is to deny them opportunities at healthy and eventful college experiences (Perske, 1972). But a community built by and comprised of supports restricts opportunities for problem solving and risk. The most social challenges exist in Tier-3 inclusion, where students have maximal control over their social engagements. When students have the choice to meet new people, they run the risk of rejection. When they seek

membership in new groups, they risk exclusion. However, when PSE programs encourage students to take greater control over their social lives, students also have the best opportunities to expand social networks and realize relationships built on equality and mutual reciprocity. Through experiencing social risk, students will also be best prepared for expanding social networks in the absence of multiple Supports. PSE programs must relinquish control and allow students the dignity of risk, because “life is only worth living if it is in the context of relationships and experiences that enable one to take risks, pursue goals, meet challenges, and make things happen” (Wehmeyer & Schalock in Wehmeyer, 2013).

The grounded theory on social inclusion describes the context under which college students with ID are most included. The most pervasive recommendation posed by the theory is that students need opportunity and choice in making social decisions. Acquiring more choice requires balanced support, skill development, and risk. Ironically, for PSE programs to accomplish their primary outcomes, Student employment and independent living, they must place limits on students’ abilities to choose an unchallenging and externally controlled social life.

### **Student Social Inclusion and Previous Research**

#### *Belonging*

Students shared a view of their social inclusion on a college campus. They described a variety of phenomena that contributed to the social inclusion grounded theory. Social networks were dynamic. Students met new social partners, contributed to their community, and found ways to stay connected, even when physically separated from others. Students

showed that college had the potential to function as a social incubator—a chance to develop practical skills, including social skills. With 200 supports and nearly 10,000 college students, the campus community was rife with opportunity for students able to access it. Student stories and the categories they produced compare with the literature on social inclusion for adults with ID with varying degrees of accordance.

Students described social inclusion as a function of belonging and attributed worth within context. Belonging was a moderator that greatly influenced perceptions of inclusion for adults with ID. Individuals who felt connected to a social network were described as less lonely when compared to similar peer groups (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). It is worrisome that people with ID have less of a sense of belonging in their communities than their non-disabled peers (Cummins, 2005). Young adults with ID from the United States' Midwest described belonging as being accepted, being talked to, being treated similarly to others without disabilities, and having positive social interactions, and when these phenomena were accessed the participants felt more included. Conversely, the absence of the attitudes and behaviors left participants perceiving themselves as less valuable and excluded.

In this study, Students described themselves as similar to their peers. They shared the same interests and activities. Students also described being socially acknowledged and invited to participate in social activities. They described themselves as sharing common experiences with peers in the campus community; like others they identified as 'college students,' a role that increased perceptions of membership even in the absence of inviting

attitudes and behaviors. With few exceptions, students perceived themselves as belonging in relationships and groups, which set them apart from the ways adults with ID living in community settings are described. College provided opportunities to meet others and to share common experiences and daily rhythms with thousands of same-aged peers. Despite having many social activities dictated by external forces, Students maintained a sense of belonging, and therefore a sense of social inclusion, with confidence and consistency not reported by adults with ID in similar studies (Abbot & McConkey, 2006; Hall, 2009).

### *Attributed Worth*

Along with belongingness, the other primary element that comprised Students' social inclusion was the worth that was attributed to them. "Worth" was used as a general term to describe whether others valued Students as people who were able to contribute in meaningful ways, whether to social interactions or broader society. Throughout the study Students formed their identities around the ways they contributed. By working, volunteering, advocating, and educating, Students explained how they used the skills they had developed to make the community a better place for everyone. As with belonging, certain behaviors exposed assessments of worth. When students were invited to events or introduced to friends of friends, they were shown to be worthy of one's time and energy. Similarly, research showed that social wellness requires acceptance (Prilleltensky, 2010). Without being accepted for all of ones strengths and limitations, people are not deemed fully worthy of participation in given social contexts. Similarly, young adults with ID have been shown to feel more socially included when they are recognized as worthy individuals, valued enough

to not be marginalized because of their differences. Membership and attributed worth are intertwined, mutually reinforcing one another to build or dissolve social inclusion within given contexts.

### *Individual skills*

‘Personal skills’ is a wide category that includes several social behaviors that can, when refined, assist in building social relationships. The amount of personal skills one has and their ability to use those skills in specific social contexts has been described variously as a barriers and benefit to social inclusion for adults with ID. In some cases, adults with ID that had under-developed social skills described themselves as lonelier (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). The associations between fewer social skills and less inclusion were commonly cited. Some adults with ID with lower literacy and low confidence, who found taking public transportation challenging, were more socially excluded because they could not access transportation needed to participate in community activities and maintain social relationships (Abbot & McConkey, 2006). Along with independent travel, other personal skills such as communication and self-advocacy skills were identified, through meta-analysis of fifteen reports, as contributing to social inclusion for adults with ID (Hall, 2009).

In this study, Students described their skills at introducing themselves and maintaining conversation. They described a willingness and interest in approaching others and building friendships. They also used technology such as Twitter, Facebook, and mobile phone texting to arrange the times and locations of social meetings. They described

themselves as proactively seeking social opportunities, whether joining clubs, going to sporting events, volunteering, or ‘hanging out’ with fraternity brothers. Often they framed themselves as primary social actors rather than acted upon. They did not wait around to be invited to events, they invited others. If they wanted a ‘movie night’, ‘game night’, or ‘girls night’ they would try to arrange the events. When interested in social events off campus, such as restaurant dining, hiking, or going to concerts, some students described their abilities to arrange transportation with Supports or friends, an essential skill in a town with few public transportation options.

Students also described specific areas where they needed more social skill development. Two students repeatedly mentioned discomfort expressing romantic interest. They described their behaviors as “inappropriate” or atypical when attracted to social partners. Supports also described Students as unable to consistently schedule meals or weekend activities with others. Other Students were either rejected or kept on the periphery of social groups because they did not understand group requirements. Rules of engagement shift from one context to another, and a lack of generalizability presented social challenges for Students. Overall, Students’ descriptions converged with the literature. A wide variety of skills were needed to develop and maintain social networks. When skills were lacking, the degree of membership or value attributed from others declined.

### *Friendship*

Students described friendship as a process and a product. Through the former, students made clear that sharing social activities with someone was not necessarily



equivalent to friendship. Relational milestones needed to be achieved before friendship was pronounced. In their campus experiences, Students became aware of Supports that viewed interactions as obligation. Credit, service hours, and case studies were earned or extracted from interactions. Only thin trust developed with Supports who used interactions with Students to achieve certain ends. More social distance was maintained between individuals with relationships defined by thin trust (Putnum, 2000). When peers remained socially distant, one Student referred to them as acquaintances, as transient and only partially engaged. Friends, conversely, chose to socially participate with Students which they did frequently, including unscheduled times. Frequent meetings with friends have been shown to decrease loneliness in adults with ID (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Too much attachment to one friend, described by two of the six students, despite the emotional closeness, has also been associated with increased loneliness (McVilly, et. al., 2006). Students had to maintain balance in their relationships and try to understand the difference between connection and codependence.

Another study examining friendships of adults with ID, found results similar to those expressed by Students. The group described 'good friends' as available across multiple spatial and social settings (Knox & Hickson, 2001). Friends shared a variety of activities. Students and Supports, describing their friendship, reported that together they exercised, ate, did homework, cheered sports teams, and explored college organized celebrations. 'Good friends' were also called lasting and dependable, and they were as likely to ask for help as provide help (Knox & Hickson, 2001). Students described their friends similarly, especially by the ways help was exchanged.

### *Valued social roles*

Like their typically developing peers, students achieved a greater sense of worth when they gave back through volunteerism and reciprocity (Bates & Davis, 2004). For Students, contributing was as much of an identity as a pathway to inclusion. Inclusion requires reciprocity; if one is viewed as having nothing to contribute then others will recognize few reasons to socially engage them. Often, people with disabilities are viewed as having little to contribute (Coleman Brown in Davis, 2010). Like other adults with ID, the Students eagerly and urgently sought to prove their value through their multiple contributions (Edgerton, 1993). By creating identity through research, Students recapitulated themselves as active helpers, not just passive recipients of help. They were givers and they used their competencies to enhance their social groups and their communities. Similarly, Hall (2009) found that young adults with ID felt most included when they held valued social roles, not just as ‘contributors’ but as competent adults, advocates, and employees.

College students show stronger degrees of friendships with those whom they believe to share a common identity (West, Pearson, Dovidio, Shelton, Trial, 2009). For Students, their valued social roles contributed to a common superordinate identification (Baumeister & Finkel, 2010). Whether the role was college student, employee, researcher, or presenter, Students felt included when they shared common identities with members of large groups. ‘College student’ was a ubiquitous and social role which contributed to Students’ senses of connection, pride, and membership. Students viewed themselves as legitimate members of the university. They wore school colors, cheered school sports teams, and they were

symbolically represented by the same mascot. As contributors, students made statements about their worth, and by sharing valued social roles, students acquired belonging.

### *Campus climate*

Students viewed the college climate as friendly, open, and accepting. They described respectful treatment and enjoyable interactions. Supports, on the contrary, observed students treated dismissively, gawked at, and even laughed at. The narratives describe different attitudinal environments existing on the grounds of the same campus. Attitudinal environments shape perceptions of social inclusion. Negative community attitudes and behaviors have long been barriers to inclusion for adults with ID, not only for the sense of loneliness they create but for the social and political marginalization they produce (Abbot & McConkey, 2006; Hall, 2009). In all instances, observations of openness were regarded as more pervasive than sporadic mockery or discrimination.

### *Social barriers*

In previous studies where adults with ID described experiences of social inclusion, barriers to inclusion were often described as the absence of the elements which contribute to perceptions of social inclusion (Abbot & McConkey, 2006; Hall, 2009). For example, if the presence of individual skills contributed to one's social inclusion, then the absence of such skills increased the likelihood for social exclusion. When transportation contributed to one's ability to participate in community activities and socialize with friends then barriers to travel increased perceptions of loneliness and isolation (Abbot & McConkey, 2006). Moreover, transportation and access to community facilities and services, which were cited as major

contributing elements to social inclusion for adults with ID in previous studies, were non-issues for Students who had equal access to campus facilities and services and could access most community activities by walking. By contrast, Students described valued social roles, opportunities to expand their social network, an inviting campus community, and individual skills as enhancing their social inclusion, all which were closely aligned with results from previous studies (Abbot & McConkey, 2006; Hall, 2009). While the absence of any element which contributed to perceived social inclusion could have contributed to perceptions of exclusion, Students did not comment on the absence of each inclusion element.

Students presented one primary barrier to social inclusion: a scheduled existence. Students described the inability to join extemporaneously constructed social activities, and Supports confirmed the barrier. This barrier related to barriers to social inclusion described by Irish adults with ID who stated they were less included when they were not allowed to make their own social plans (Abbot & McConkey, 2006). Students were allowed to make social plans but were given few opportunities to practice the skill. Hall (2009) conversely noted that young adults with ID felt included when they were given opportunities to self-advocate. Schedule construction is a form of self-advocacy, where students chose relational partners and social activities, but the restriction of such opportunity, as stated by students, reduced perceptions of social inclusion.

Supports, on the other hand, observed more barriers to Students' social inclusion. None of the barriers mentioned aligned entirely with commonly cited barriers in the research. In addition to Students' lack of social spontaneity, Supports reported that positive attitudes

and the desire to participate with Students would increase if members of the campus community had more opportunities to build rapport with students. Superficial or short interactions were not sufficient to know Students as individuals, and Supports felt more frequent exposure with Students would also improve positive attitudes about people with disabilities. Supports felt when students were congregated together they were more likely to be stereotyped and seen as not belonging with typically developing peers. Also identified by Supports was their role in disempowering students. Supports felt that they participated in 'faux' inclusion. Cummins & Lau (2003) described relationships between adults with disabilities and community members without disabilities as doomed to feel unnatural because the groups would not typically share social contexts because of different lives and interests. Supports and Students recognized their commonalities, but Supports described 'watered-down' or 'fake' inclusion as occurring out of the desire to make Students feel included. They recognized that such treatment, while resulting in Students sense of importance, portrayed Students as inherently different which had a negative impact on belonging, worth, and therefore, social inclusion. Rather than encouraging more social interactions with others with disabilities, as Cummins and Lau (2003) suggested, Supports saw it necessary to advise the PSE program to avoid inclusion activities for Students that would not naturally occur for their peers in the campus environment.

The result of barriers to social inclusion is social exclusion. Exclusion was described by young adults with ID as being left out, as not being allowed to fully participate in the same ways as others (Hall, 2009). Others recognized exclusion as the result of barriers to

autonomy and restrictions of social movement (Welsby & Horsfall, 2011). Students rarely described feeling lonely or left out, but when they did it was because they wanted to participate in an activity but felt like they were restricted. Exclusion, at the individual level, was described as a sense of temporary alienation, but at larger social levels exclusion limits opportunities for engagement and participation of individuals with ID. The goal of the current research was to advance the understanding of social inclusion to ameliorate exclusion and individual, institutional, and political levels.

### **Limitations**

#### *Photovoice*

The photovoice process valued Students as purveyors of knowledge. Students commented on elements of their social lives they saw most important, and in the process added meaning to their college experiences and found the opportunity to actively construct their identities. Though a symptom of intellectual disability is limitations in abstract thought and communication (AAIDD, 2011), the SHOWeD process guided students from describing concrete elements of photographs to describing the symbolic meaning embedded within photos.

Nonetheless, Photovoice remained an imperfect data collection process. A limited number of photo release forms were returned to the researcher, rendering some photographs unavailable for research purposes. Despite the freedom to collect data at almost any moment through digital photography, photo release forms were not as conveniently transported and often unavailable. Students often carried research materials in a binder that they kept in their

backpack. Students who carried backpacks to social and extracurricular events would have been atypical to peers in similar situations. By demanding that Students carry photo release forms, research increased Student ‘otherness’ Often Students avoided potential stigma by not carrying forms at all times. Consequently, about a third of photographs that required photo-release attained it—a product of cumbersome forms and non-influential training. Future research should consider electronic photo-release forms where digital signatures can be collected through mobile devices such as cellphones and tablets.

Photographs were not content analyzed; their purpose was for narrative elicitation. Interviews were the primary method in the Photovoice process, meaning spoken communication was prioritized. Interviews placed two Students at a distinct disadvantage because they had a limited vocabulary or did not use complete sentences to express thought. Communication was also related to social skills. Some students were still learning strategies for holding conversations, including using more descriptive language to communicate needs and desires. Half of the interviews were primarily driven by probing questions. Under such circumstances, the researcher was more likely to choose the direction of discussed social content. Qualitative analyses are also dependent on detail and description to form and constantly compare codes. Students with less descriptive language produced shorter transcripts, which are easily construed as less rich or lower quality. Such perceptions of data and those who produce data perpetuate the devaluation of people with ID. When more is viewed as better and efficiency (e.g., words produced per interview) is associated with value, adults with ID or communication limitations are deemed less valuable—they have less influence over aggregated data analysis and emergent codes. Methods should not determine

the degree to which one's voice and preferences are amplified. If participant researchers who generate less data are viewed as less useful or less important, then research is not emancipatory, it replicates society's worst assumptions about people with disability. Participatory research methods should provide opportunities for equity and social justice, but methods and analyses remain discriminatory until modified to maximally include all participant voices. When not individualized for participant strengths, research and evaluation will remain discriminatory in method and prejudicial in analysis.

### *Supports*

Paid and unpaid Supports for Students were comprised primarily of women. Women are more likely to have favorable attitudes towards people with disabilities (Siperstein, Parker, Bardon, & Widaman, 2007; Morin, Rivard, Crocker, Boursler, Caron, 2013). Women were also overrepresented in academic disciplines, such as education, psychology, nursing, and communication sciences, that were commonly affiliated with the PSE program. Supports who participated in questionnaires and focus groups were also overwhelmingly women. The lack of variability may have contributed to different quantitative and qualitative data than would have been found in a more diverse Support sample.

While Supports are more informed than any other population on the campus about Students' experiences, they will still be reporting subjective perceptions on inclusion. While this study invited subjectivity, knowledge creation, and meaning-making, Supports still may have been hesitant to report instances of Student loneliness and exclusion for the belief that such observations were a reflection on their effectiveness as Supports. Additionally, the investigator was a member of the PSE program staff. Even though consent forms clearly



stated that responses would have no bearing on Support status or employment with the program, the potential for power relations to impact responses was ever present.

Finally, alterations were made to existing social support and loneliness instruments. Measures were originally constructed for subjects to self-report their experiences, but wording was altered for Supports to report perceptions of Students' social experiences. Changing the questionnaire invited observations of a community of Supports while reducing error that might have been associated with changing wording and reducing item complexity for Students. The cost, however, was that assessing and commenting on other's social lives is inherently problematic. Observers can only observe social situations and theoretically have little or no access to instances when Students' were alone or excluded because, by definition, such instances would remove Students from the social sphere. Moreover, the reliability and validity is unknown for instruments altered.

### *Delimitations*

The PSE program was a two-year experience for all students, but by the time Students began collecting and presenting photographs on their college experiences, they were in their second or fourth university semesters. Because Students did not collect data on their social experiences throughout their college experience, results only reflect the social experiences of more experienced Students. Transition is difficult for all college students, especially in their first semester. However, the results of this study cannot inform practices and procedures to best help students with ID acclimate to new college experiences and social networks. The benefit of later-stage perceptions of inclusion, is that they likely reflect more stable day-to-day experiences that were not dramatically influenced by acute perceptions of isolation or

loneliness that could be associated with the first few weeks for any student living on a college campus.

Because little outcome data has been collected to prove the effectiveness of PSE programs, it is unclear to state the degree to which skills acquired in the college setting can be generalized in community. Much of the discussion suggested that Students who have more control over their social experiences in college would be better prepared to sustainably build and maintain social networks after college. However, college is not society. Life is qualitatively different on college campuses and there is no clear indication that skills and strategies that are effective for Students with ID in college are even applicable to independent living in community settings.

#### *Recommendations for Future Study*

When methods are more accessible, participants with disability have a better opportunity to construct knowledge and guide changes in procedures and policies affecting their life quality. Image Grouping, collection of interactive image-based exercises, makes research more accessible for individuals with lower literacy (Minnesota Department of Human Services, 2013). Through image grouping, survey items are made more accessible. Rather than selecting abstract, scaled responses, participants have the opportunity to place a sticker along an answer continuum anchored with pictorial images. The process makes more concrete the process of responding to survey items by not relying on respondents' abilities to read or understand relative differences in ordinal response options. The physical line representing the continuum between anchors can be equally subdivided to relate respondent's sticker location to corresponding scaled responses. For example, a continuum divided into

five equal parts would correspond with a five-point Likert scale. Once data are transformed to numerical form they can be analyzed similarly to any survey responses. Image Grouping has also been used in interviews and focus groups (Minnesota Department of Human Services, 2013).

With more accessible response options, proxy respondents are less useful, and people with disabilities are more able to directly report their experiences. Universally designed surveys open new possibilities for measuring social inclusion for adults with ID. In this study, Students described a sense of belonging as a primary contributor to perceptions of social inclusion. Therefore, rather than measuring social support as a way to examine Student connectivity, belongingness measures could be directly administered to students. One measure that could be given to college students with ID is the General Belongingness Scale (GBS), a twelve-item, two factor measure (Malone, Pillow, & Osman, 2012). The reported factors underlying the belongingness construct were Acceptance/Inclusion and lack of Rejection/Exclusion, which were shown to predict life-satisfaction (Malone, Pillow, & Osman, 2012). Responding to similar belongingness or sense of belonging measures has the potential to increase understanding of social inclusion for adults with ID who live in multiple settings, including college environments. Future studies can improve quality of life of adults with ID by better adapting research methods, quantitative and qualitative, to assure opportunity to participant and contribute the factors that enhance or compromise well-being.

## Conclusion

In the Spring of 2012 Students collected visual data to help them describe the nuances of their social experiences in a college community. Since then, all participant-researchers have graduated from the PSE Program, but their legacy remains. By making meaning and sharing experiences, the PSE program has made changes to increase Student involvement in daily activity schedule-making. Each week students meet with a Support scheduler and provide lists of social activities in which they desire to participate. Students have greater power to choose with whom and how they spend their time in college. While Students are expected to attend all of their classes and work, they also reserve the right to change any social activities on their schedule, allowing them to participate in activities with friends that were not planned at the time schedules were constructed.

Students were taught how to collect data, but they made meaning of social experiences in ways that emphasized the people they were and wanted to be. They defined social inclusion in their campus communities. Relationships, actions, identities, and procedures that contributed to their perceived social inclusion were documented and used to create grounded theory on social inclusion for college students with ID. Methods were not perfect, but they allowed Students to construct social inclusion in ways that best suited their needs. Students were not objective reporters. Their collective construction of social inclusion was meant to make change—change in beliefs about their position in the college community and change in the PSE program that facilitated their experiences. To those ends, the research was moderately successful. Students learned about themselves and acquired new skills, and

they contributed a vision of their social experiences that has already resulted in procedural changes.

At the study's conclusion, Students took opportunities to disseminate their social inclusion findings. Some wrote and published their experiences, and others spoke at local and national conferences. They self-advocated for participation in program evaluation and they promoted inclusion for students with intellectual disabilities in all colleges and universities. In the summer of 2014, three Students even went to speak to organizations and universities in England and Ireland to share their experiences of inclusion in the college setting. The research served as a path to personal and program development in ways that enhanced student quality of life. Through describing and sharing their social experiences, students captured the power of social inclusion as an outcome and precursor of wellness (Prilleltensky, 2010).

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## APPENDICES



Appendix A.

Photovoice Consent Form

**[PSE] Program Participatory Evaluation Project**

You are invited to take part in an evaluation project conducted by Seb Prohn, academic coordinator for 'The University's' [PSE] Program. In this evaluation project, you and other participants will take pictures and discuss them with Seb with the goal of improving the [PSE] Program and 'The University'. This type of evaluation is sometimes known as 'photovoice'. This is a chance for you to teach others about your life and experiences as a college student.

This evaluation will also provide participants with the opportunity to use their voices and opinions to bring greater awareness to their experiences and needs. You are invited to be a part of the project on a voluntary basis only. The following are some answers to general questions about the evaluation and the roles of the participants.

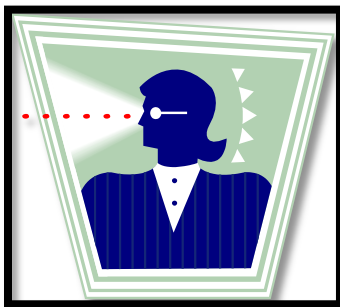
	<p><b>What is my role?</b> At first you will learn how to take photographs that communicate your views. You will use a digital camera, phone or iPad to take photographs of your social experiences in college. Sometimes this means you'll even be taking pictures of the things you do when you are alone. You will then select pictures that you would like to share and you'll discuss these pictures with Seb every week. During discussions you'll explain why you took your pictures and what the pictures communicate. To capture what you say the discussions with Seb will be audio taped. You may also be asked to share your photographs and thoughts.</p>
	<p><b>What is the purpose of taking pictures?</b> The pictures are taken as a way for you to identify strengths and concerns as they relate to your inclusion on The University's campus. The photographs will educate [PSE] Program's Staff members, The University community members and others about the issues that either prevent or support your social inclusion in The University campus community.</p>





**How will my photographs be used?**

Your photographs will be used to start interesting conversations about your membership, support and involvement in The University's campus community. Some photographs may be included in public exhibits, presentations or publications. You need only share and photograph what you consider to be appropriate and comfortable. All of the photos that you take as part of the evaluation project are yours. You have full ownership of the photographs and have a right to decide which ones will be used for public display. With your permission, some of your photographs will be used for this evaluation.



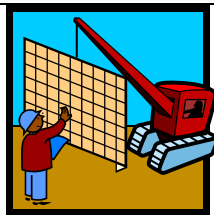
**How will my name or identifying information be used?**

Your name and identifying information will not be shared with your photographs and college stories included in exhibits, presentations or publications unless you request the use of your first name or a made up name, called a pseudonym. It is good to remember that despite efforts of confidentiality, there is always the chance that somebody may recognize you in the photographs.



**How long with this evaluation project last?**



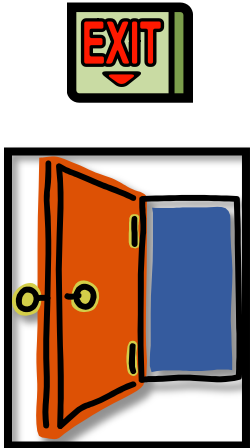

The project will last at longest through the spring 2013 school semester.





**UP**

**What are the benefits and risks of partnering in this evaluation project?**

If you want printed copies you will receive copies of your photographs. You will learn about doing research in the college environment. You will be able to tell your own stories related to your photographs, express your feelings and opinions that will help make the [PSE] Program and The University best support present and future UP participants. The main risk is that someone will recognize you in the photographs.

	<p><b>Will I be paid for participating in this evaluation project?</b>  You will not be paid for participating in this evaluation project.</p>
	<p><b>How will the information be stored?</b>  Information collected during the discussions with Seb will be stored on a password protected computer and in files designated for this project. Access will be limited to the researchers. All data stored in computers will have password protection and all paper files will be secured in a locked storage file.</p>
	<p><b>What if I change my mind and do not want to share photographs or participate in discussions with Seb?</b>  If at a later date, you do not wish to share your photographs with others or participate in discussions you may contact PSE Program coordinator (XXX-XXX-XXX; XXX@email.edu) and all accompanying information will immediately be removed from the project data. You do not have to give any reason for not wanting to participate any longer. If you wish to participate in the project and do not want your pictures or stories used for research, you may do so. You may also withdraw from the project at any time and there will be no negative consequences.</p>
	<p><b>Has this project been approved by an Institutional Review Board (IRB)?</b>  Yes, this study has been approved by the Institutional Review Board of the University. This is a committee that oversees research projects to ensure that the rights of the participants are protected. If you have any questions about your rights as a research participant, you may contact the IRB compliance officer, _____, The University</p>

	<p>(<a href="mailto:xxx@email.edu">xxx@email.edu</a>; (XXX) XXX-XXXX).</p>
	<p><b>Who is directing this project?</b> The director is Seb Prohn from the [PSE] Program and The University. But please think of yourself as a co-director of this research because with your voice you have the ability to make changes in the way the research is done and the types of questions that are asked.</p>
	<p><b>How do I provide consent for my participation?</b> If you are interested in participating in this evaluation project, please read (or have someone read to you) the following agreement statement, sign, date and return this form. You will receive a copy of the form should you have any question or concerns at a later date.</p>

### Agreements statement

By signing this consent form, I agree to participate in the evaluation. I also understand and agree that, unless otherwise notified in writing, I am giving The University and the [PSE] Program unlimited permission to copyright and use my photograph(s), interview(s), and accompanying stories for public exhibits, presentations, publications and/or other educational purposes.

By signing this form, you agree to fully participate in the photovoice evaluation by doing the following activities:

- Meeting weekly with Seb
- Arrive on time to meetings
- Take pictures of your university experiences
- Discuss your pictures with Seb
- Have your thoughts audio recorded for the evaluation
- Share your photos with the campus community and other educational communities
- Follow project rules and guidelines, especially as they pertain to receiving permission to take and use photographs of other people in your photographs.

Remember, your participation is completely voluntary. Signing this paper means that you have read this and that you want to be in the research project. This is your decision! It is OK if you don't sign the paper or if you change your mind later.

Print name of Participant: \_\_\_\_\_

Signature of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Print name of Guardian: \_\_\_\_\_

Signature of Guardian: \_\_\_\_\_ Date: \_\_\_\_\_

**Thanks for your time and help!**

## Appendix B.

### Surveys

Modified Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)

1. There is a special person at The University who is around when Students are in need.
2. There is a special person at The University with whom Students can share their joys and sorrows.
3. Students' families really try to help them.
4. Students get the emotional help and support they need from their families.
5. Students have a special person at The University who is a real source of comfort.
6. Students' friends at The University really try to help them.
7. Students can count on their friends at The University when things go wrong.
8. Students can talk about their problems with their families.
9. Students have friends at The University with whom they can share their joys and sorrows.
10. There is a special person at The University life that cares about Students' feelings.
11. Students' families are willing to help them make decisions.
12. Students can talk about their problems with their friends at The University.

MOS Social Support Survey (Sherbourne & Stewart, 1991)

How often is each of the following kinds of support available to Students when they need it?(never, rarely, sometimes, most of the time, always)

1. Someone to have a good time with
2. Someone to give Students information to help them understand a situation
3. Someone to confide in or talk about themselves or their problems
4. Someone to get together with for relaxation Someone you can count on to listen to you when you need to talk
5. Someone to whose advice they really want
6. Someone to do things with to help them get their mind off things
7. Someone to share their most private worries and fears with
8. Someone to turn to for suggestions about how to deal with a personal problem
9. Someone to do something enjoyable with
10. Someone who understands their problems

Modified UCLA loneliness scale version 3 (Russel, D.W, 1994)

1. How often are Students 'in tune' with people around them? (R)
2. How often do Students lack companionship?
3. How often are there no one Students can turn to?
4. How often do Students feel alone?
5. How often are Students part of a group of friends? (R)
6. How often do Students have a lot in common with the people around them? (R)
7. How often do Students no longer seem close to anyone?
8. How often are Students' interests and ideas not shared by those around them?
9. How often are Students outgoing and friendly? (R)
10. How often do Students feel close to other people? (R)
11. How often do Students feel left out?
12. How often are Students' relationships with others not meaningful?
13. How often does no one really know the Students well?
14. How often are Students isolated from others?
15. How often can Students find companionship when they want it? (R)
16. How often are there people who really understand Students? (R)
17. How often are Students shy?
18. How often are people *around* UP Participants but not *with* Students?
19. How often are there people around that Students can talk to? (R)
20. How often are there people Students can turn to? (R)